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**Exploring the close relationships of people with
learning disabilities: A qualitative study.**

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Doctorate in Clinical Psychology
University of Edinburgh
August 2012

I declare that I am the sole author of this thesis and that the work contained herein is my own. This thesis or any part of it has not been submitted for any other degree or professional qualification.

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1.0 ABSTRACT

Introduction: Interpersonal relationships are beneficial for people with a learning disability (PWLD), acting as a protective barrier against transition difficulties, social stigma and negative outcomes such as physical and mental health problems. The social networks of PWLD are, however, often more restricted than those of the general population. There has been very little research which has explored the views and experiences of PWLD about their social and sexual relationships. A systematic review of the qualitative research surrounding the sexual relationships of PWLD was conducted. Eleven studies were reviewed, which revealed five themes: 'A lack of knowledge regarding sexual relationships', 'Sexual relationships as restricted and regulated', 'Sexual relationships perceived as wrong', 'Sexual relationships being desired', and 'Sex as a negative experience'. Positive developments in the attitudes of others and supports were described, but the impact and influence of stigma, assumption, ignorance and a lack of autonomy regarding sexual relationships were dominantly reported. However, the findings of the reviewed studies must be considered with caution due to methodological limitations. The current study aimed to build on the existing qualitative research by exploring the experiences and perceptions of both sexual and close relationships for PWLD.

Method: Data were gathered from ten PWLD using one to one semi-structured interviews. Interviews were recorded, transcribed and analysed using Interpretive Phenomenological Analysis.

Results: Five super-ordinate themes were identified; 'Relationships feeling safe and being useful', 'Who's in charge?', 'Struggling for an ordinary life', 'Touching people in relationships' and 'Hidden feelings'. The findings were shared with participants who confirmed their relevance in the lives of PWLD. 'Touching people in relationships' is presented separately within a journal article format.

Discussion: The findings suggest that fundamental components of close relationships were feeling safe and receiving some form of positive gain. The lack of agency participants

experienced limited the development of these aspects, whilst also preventing the ability to live an 'ordinary existence', which included physically intimate relationships for many individuals. Finally, participant's feelings were generally unclear, which could be related to being interviewed by a relative stranger or emotional expression difficulties. Based upon these findings it is considered that those who support PWLD should focus their assistance on addressing negative attitudes and redressing the power imbalance to facilitate an 'ordinary existence' for these individuals, which may indirectly enable them to naturally develop safe and useful relationships. It is also possible that reducing the barriers and stigma surrounding close relationships would open up communication regarding this area, which could indirectly promote PWLD ability to express their emotions regarding relationships.

Conclusions: The research provides a greater insight into the lived experience of close relationships for PWLD. Participants valued close relationships that were safe and useful, but their ability to develop and maintain these was described as being restricted by other people and service rules. It is proposed that those supporting PWLD need to balance protective action against the freedom and choice required to develop and maintain close relationships, as restricting the already limited social networks of this population will negatively impact upon their quality of life.

2.0 TERMINOLOGY AND FORMATTING

Although the term ‘learning disability’ is widely used amongst professionals within the UK, several terms have been used to describe this population throughout the research portfolio. Within the systematic review ‘intellectual disability’ is used as this is the term used by the journal where the paper is intended to be submitted for publication. The term ‘learning difficulties’ is also used within several of the appendices, as these documents were presented to members of People First Scotland, an organisation which has actively chosen to use this label to emphasise that the difficulties their members face are located within the social environment and not the individual alone. Outside of these areas the term ‘learning disability’ has been used.

The formatting and referencing styles used throughout the portfolio also vary, in relation to the author guidelines of the journal in which the article is intended to be submitted. Where sections have adopted a particular journal style this has been indicated at the start of the section. The author guidelines have also been provided within the appendices (Appendix O(a) and O(b)). The remaining document is formatted referenced in accordance with the British Psychological Society (BPS) style guide (BPS, 2004).

3.0 SYSTEMATIC REVIEW

Title.

The sexual relationships of people with intellectual disabilities: A systematic review of qualitative studies.

Written in accordance with author guidelines for:
Journal of Applied Research in Intellectual Disability.

Abbreviated title for running head:
Sexual relationships: A systematic review

3.1 Abstract

Background: Historically, the expression of sexuality of people with an intellectual disability (PWID) has been discouraged. Government policy and the influence of the self-advocacy movement means that individuals with Intellectual Disabilities are increasingly asserting their rights to sexual expression. This review collated the findings of qualitative research regarding the sexual relationships of PWID.

Materials and Method: Five electronic databases were searched. Eleven studies were reviewed and the main findings collated.

Results: A narrative synthesis of results revealed five main themes in relation to sexual relationships: ‘A lack of knowledge regarding sexual relationships’; ‘Sexual relationships as restricted and regulated’; ‘Sexual relationships perceived as wrong’; ‘Sexual relationships being desired’ and ‘Sex as a negative experience’.

Conclusions: The review identified some supportive attitudes. However, most participants described the direct impact and influence of stigma, ignorance and a lack of autonomy regarding sexual relationships. Findings must be considered with caution due to methodological limitations.

Key words: Intellectual disability, sex, relationship, qualitative, review, perceptions.

3.2 Introduction

Experiencing sexual relationships has been said to be a human right which contributes to an individual's self-identity and self esteem (Yau *et al.* 2009). While many people with an intellectual disability (PWID) are capable of, and show, a desire for sex and sexual contact (Craft, 1987), they often encounter limited opportunities to develop and maintain such relationships (Lafferty, 2008), leading to isolation and loneliness (McCarthy & Thompson, 2010). This may be due to a number of factors including the historical belief that PWID were 'eternal children' (McCarthy, 1999; Yau *et al.* 2009) who did not experience sexual feelings (Bunyan *et al.* 1986; McCarthy, 1999). Or that society needed to be protected against people with intellectual disabilities (ID) pronounced sexuality (Lesselier & Van Hove, 2002). As such, sexual expression and relationships were openly discouraged in this population (McCarthy, 1999) during this time. More liberal attitudes surrounding sexuality began developing in the 1960's which was reflected in an increase in the development of sex education materials for PWID (McCarthy, 1999). During this period the position of service providers largely shifted from the complete denial or overt repression of sexual expression in this population, to the management of their sexuality (McCarthy, 1999). This was done both indirectly through a lack of education or support to reach psychosexual maturity, and directly through limitations, rules and restrictions regarding an individual's sexuality. Brown (1994) suggests that such management actually resulted in the sexual options of PWID remaining relatively unchanged.

The indirect management of sexuality may result from staff feeling uncomfortable or under qualified to discuss sexuality (McCarthy & Thompson, 2010), anxiety regarding the legal issues that surround sexuality (McCabe, 1999) or that discussing sex might result in sexual behaviours that could be difficult to manage (Kitson, 2010). Thus, PWID commonly experience a lack of information (Aunos & Feldman, 2002) guidance and support (Bunyan *et al.* 1986). This not only restricts an individual's ability to develop the skills to form appropriate consenting relationships (Kitson, 2010) but may also increase their potential to perform illegal or socially unacceptable behaviours (Bunyan *et al.* 1986) and their vulnerability to abuse (Owen *et al.* 2000; Healy *et al.* 2009; Kitson, 2010). Indirect management may also result from those delivering sex education programmes focusing on the more practical and negative elements of sexuality or promoting stereotyped behaviours, such as males being dominant in couple relationships and sexual encounters (McCarthy, 1999; Bane *et al.* 2012). Sex education can also promote culturally dominant discourses, such as sex only occurring within marriage (Owen *et al.* 2000), or sex being wrong or dirty (Yau *et al.* 2009).

The direct management of sexuality may occur through the way services are structured, for example limiting privacy or relationships being assessed, sanctioned or otherwise by professionals (Hollomotz & The Speakup Committee, 2008). These services are generally driven by the concerns of professionals in relation to the high risk of PWID being maltreated and sexually abused (Horner-Johnson & Drum, 2006). However it is important that the consequences of high levels of protection are considered, such as PWID having very little choice or control over their sexual relationships (Healy *et al.* 2009; McCarthy & Thompson,

2010). Further, the rules, restrictions and close monitoring designed to protect can actually encourage PWID to conduct sexual relationships in secret or unsafe ways, for example, developing relationships quickly or performing sexual acts in public spaces (McCarthy, 1999; Hollomotz & The Speakup Committee, 2008).

Despite these barriers PWID are increasingly in control of their sexual lives (McCarthy & Thompson, 2010) and are more commonly being seen as agents in their own lives (Lessliers *et al.* 2010). This change has been influenced by the self-advocacy movement (McCarthy, 1999), is reflected in government policy (Scottish Executive, 2000; Department of Health, 2001; 2009) and has also been documented in a growing body of qualitative research literature, which has focused on the experiences and perceptions of sexuality and sexual relationships of PWID.

3.2.1 Aim of the current review

The current paper systematically reviews the findings of qualitative research regarding sexual relationships in PWID, with the aim of consolidating the findings of current research and increasing awareness of the experiences and perceptions of PWID surrounding sexual relationships.

3.3 Materials and methods

3.3.1 Search strategy, data extraction and quality assessment

The systematic review was conducted based upon the guidelines of Petticrew and Roberts (2010) and the Centre for Reviews and Dissemination (2009). Five online databases were used to identify appropriate studies: ASSIA, CINAHL, EMBASE, MEDLINE and PsychINFO, which was conducted in May 2012. Four search terms were selected to capture a broad range of relevant articles: Intellectual Disability; Sex; Relationship and Qualitative. Synonyms and specifiers (mainly identified using the related term function within Ovid SP) for each of these terms were also searched to ensure that all relevant literature was accessed (see Table 1 for key words used). In addition, the reference lists of relevant studies and contents of key intellectual disability journals (British Journal of Learning Disabilities, Disability and Society, Learning Disability Review) were hand searched. The identified studies were then screened for relevance using study titles and abstracts. The inclusion criteria for the review were: peer reviewed articles published in English; a primary research question focusing on sexual relationships; utilisation of a qualitative design, and interviews with adult participants with intellectual disabilities. Articles that did not meet these criteria were excluded from the review. This final stage involved the extraction of data and appraisal of identified studies for quality. Information including research aims, sample size, participant characteristics, research context, study design, analysis method, research findings and conclusions were extracted. These aspects are illustrated within Table 3.2.

Table 3.1: Key word used during search of online databases.

Search term	Key Words
Intellectual Disabilities	<i>learning disabilit*, learning disorder*, mental retardation, mental deficiency, mentally disabled person*, developmental disorder*, developmental disabilit*, special needs, intellectual impairment, learning disabled, developmentally disabled, intellectual disabilit*, mentally retarded, mentally handicapped</i>
Sexual	<i>Sexual, heterosexual*, homosexual*, bisexual*, psychosexual behavio*, intimacy, intimate</i>
Relationship	<i>Relationship*, interpersonal relation*, human relation*, human courtship, male female relations, courtship, dating, romantic relationship*</i>
Qualitative	<i>Focus group*, Interview*, Voice*, Qualitative</i>

A quality appraisal check list (Appendix A) was used to appraise studies, as recommended by Chenail (2011). However, as it is considered “unwise to consider any single set of guidelines as definitive” (Mays & Pope, 2000, p. 52) check list criteria were developed through the consideration and amalgamation of several existing models and guidelines (Yardley, 2000; Mays & Pope, 2000; Critical Appraisal Skills Programme, 2006; Yardley, 2008; Tracy, 2010). Ten criteria were developed (Appendix A) and outcome ratings, developed from rating systems used by Cesario *et al.* (2002) and the Scottish Intercollegiate Guidelines Network (SIGN, 2008), were assigned on the basis of these. A score of 3 was awarded when criteria were ‘well addressed’, 2 when ‘adequately addressed’, 1 where criteria were ‘poorly addressed’ and 0 if the area was ‘not reported’ or non-applicable. The total scores of the ten appraisal criteria were then graded. Studies that acquired a total score above 22 were awarded a ‘++’ grade, indicating that between 75% and 100% of the criteria were met, suggesting good methodological quality. A ‘+’ grade was allocated to studies that obtained scores between 15 and 22, indicating that between 50% and 74% of the criteria were met and suggesting average methodological quality. Studies with a score of 15 or below were assigned a ‘-’ grade,

indicating that less than 50% of the criteria were met, suggesting poor methodological quality and that the research is likely to be significantly flawed and vulnerable to the impact of bias. An independent qualitative researcher second rated a sample of the articles reviewed (4 papers), which were selected at random. The overall quality rating scores differed by one point for three of the articles. Overall there was a high level agreement between the raters (80%). Table 3.3 documents the quality assessment ratings for the studies review.

3.3.2 Synthesis of Findings

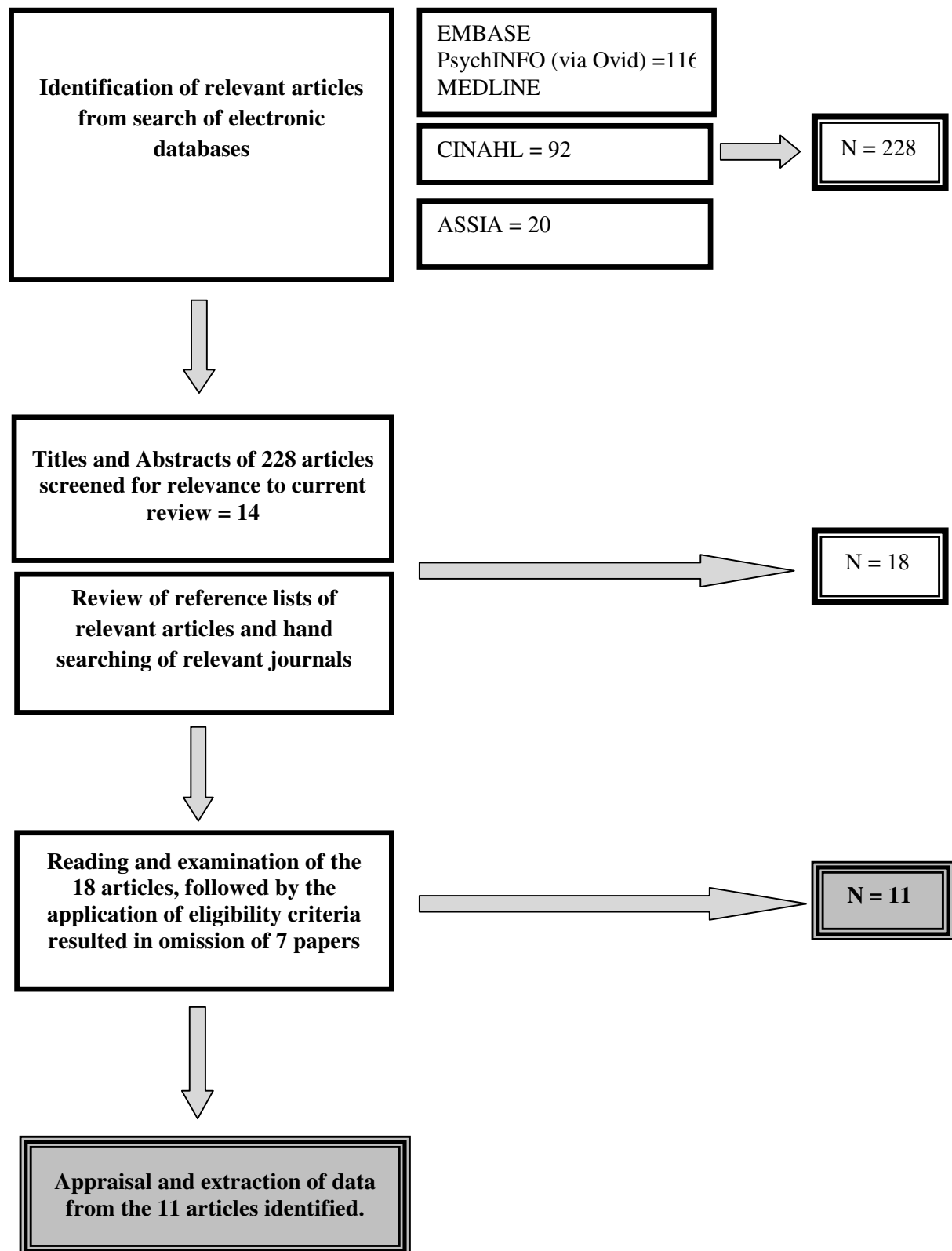
As the studies within this review are heterogeneous in their design and analytical methods a narrative synthesis was conducted, as recommended by Petticrew and Roberts (2010).

3.4 Results

3.4.1 Included studies

Initially 228 studies were identified as potentially relevant. Screening for relevance identified 14 articles. An additional 4 papers were identified using other search methods. The application of the eligibility criteria resulted in six articles being omitted as the research did not focus directly on sexual relationships (Davidson-Paine, 1995; Knox & Hickson, 2001; Ward *et al.* 2010), did not use qualitative methodology (Timmers *et al.* 1981), included interviews with carers (Löfgren-Mårtenson, 2004), included a sample of 13-17 year olds (Healy *et al.* 2009) and one being omitted as it was a re-publication of data, with the earlier briefer paper being removed (Lesseliers,1999). This resulted in 11 articles being included within the current review, as summarised in Figure 3.1.

Figure 3.1: A summary of the review process



3.4.2 Study characteristics

Table 3.2 presents a summary of the studies included within the review.

Table 3.2: Summary of Reviewed Studies

Study	Aims	Sample Size	Participant Characteristics	Context	Study design	Qualitative analysis method	Main findings/themes	Conclusions/clinical implications
1. Thompson (2001)	To obtain Men's descriptions of sexual contact with other people.	"about 140".	Males with ID attending services for sex education /counselling. All with experience of sexual behaviour.	Recruitment: through services. Location: not documented. Data collection: not documented.	Interviews (during clinical practice).	Not documented	<ul style="list-style-type: none"> • One script for sex, Men 'do' sex to women or a less powerful man. • Lack of care re: partner's pain/pleasure nor consequences. • Little communication re: sex. • Sexual identity not a focus for individuals. • Sex as physical rather than emotional act. 	<ul style="list-style-type: none"> • Importance of understanding the ID male's experience of sex if support is to be effective. • Importance of looking at findings in context.
2. Fitzgerald & Withers (2011)	To investigate the sexuality and sexual identity of women with ID.	10	White, British women with ID. Aged between 19 and 64 yrs. All could comprehend and communicate verbally.	Recruitment: through professionals working in local services. Location: not documented. Data collection: interview conducted in location chosen by participant.	Two semi-structured interviews.	Thematic analysis.	<ul style="list-style-type: none"> • Women could not conceptualise themselves as sexual beings. • Tended to regard sex a dirty and an inappropriate activity for them. • Belief that others prohibited them from engaging in sexual activity. • Considered themselves to be of little value and had no clear sense of identity. 	Need for services to find ways to empower women with ID to acknowledge welcome and take control of their own sexuality.

Study	Aims	Sample Size	Participant Characteristics	Context	Study design	Qualitative analysis method	Main findings/themes	Conclusions/clinical implications
3. Lesseliers & Van Hove (2002)	To investigate and interpret the world of people with ID by understanding the meaning they attach to their relationships and sexual lives.	46 (34 analysed).	Adults labelled mentally retarded. Ages 20-65 years. 23 women 11 men. Living in a range of group accommodation in the community. All receiving support. Able to comprehend and communicate verbally.	Recruitment: through staff at residential and day facilities. Staff decided who could participate based on verbal abilities before contacting researcher. Location: Flanders, Belgium. Data collection: interview in empty work shop or visitor's room. Not stated if known location for participants.	Semi-structured in depth interviews.	Mixed method (inc. Grounded Theory).	<ul style="list-style-type: none"> • Loving and being loved as positive thing. • Sexuality as limited by self and regulated by other. • Experiences of sexual intimacy as variable. • Little power/choice regarding relationships. • Absence of advice/support re: relationship. • Guilt and disapproval re: masturbation. • Presence of sexual abuse. • Marriage and children as limited or regulated. • Need for sex education. 	<ul style="list-style-type: none"> • PWID should have choice in where and who they live with. • Space for privacy and intimacy in residential settings. • Policies should be consistent with human rights position. • Provision of adequate and continuous sex education and relationships counselling. • Need to train others who influence relationships of PWID to develop respectful and supportive attitudes.
4. Wheeler (2007)	To explore how groups of men with ID experienced their sexuality and sexual identity using IPA.	12.	White British men. Aged 16-42 yrs.	Recruitment: self- elected from three self-advocacy groups. Location: Semi-rural ex mining towns in south Wales. Data collection: interviews took place in "home grounds" of participants.	Literature review. Focus groups. In-depth semi-structured interviews.	Interpretive Phenomenological Analysis.	<p>Similarities between themselves & men without ID</p> <ul style="list-style-type: none"> • Trust. • Ideal body image desired. • Sexual beings. • Perception of love as varied. • Cohabiting, marriage & children <p>Differences between themselves and men without ID:</p> <ul style="list-style-type: none"> • Being different restricting, relationships, occupation, life, having a child. • Independence, relationships, sexuality & having children restricted by others. 	Common themes emerged across sample and with other men who do not have ID, such as their desires and aspirations, and their perception of being sexual beings, not asexual.

Study	Aims	Sample Size	Participant Characteristics	Context	Study design	Qualitative analysis method	Main findings/themes	Conclusions/clinical implications
5. Johnson <i>et al.</i> (2002)	To identify key issues around sexuality and relationships for PWID. To develop trial and evaluate workshops to assist them to live safer sexual lives.	25.	12 men 13 women with ID. Aged 25-60 yrs.	Recruitment: not documented. Location: Australia. Data collection: not documented.	Participant action research (PAC). Life stories, provided by participants over 3 sessions.	Not documented	<ul style="list-style-type: none"> Attitudes of service providers and families present obstacles to PWID leading sexual lives or developing relationships. Lack of accurate information about sexuality available to PWID. Lack of clear policies and guidelines for staff working with PWID. Experience of loneliness and isolation. 	<ul style="list-style-type: none"> PAC project was innovative, from which the interventions made enable significant steps to be taken in relation to helping PWID lead safer sexual lives. Project was unable to increase social opportunities for this group of people.
6. White & Barnitt (2000)	Do PWID feel empowered or discouraged when they engaged in an intimate relationship?	8.	7 community residents and 1 in a residential home. Aged 18-35 years old. Two couples.	Recruitment: self-elected from social club for PWID. Location: not documented. Data collection: topic selected by participants. Couples interviewed together.	Semi structured interviews (two forms delivered dependent upon experience of individual)	Four readings analysis method.	Themes analysed/ discussed: <ul style="list-style-type: none"> The experience of intimate relationships. The future of current relationships. The involvement of others in relationships. Positive and negative views of relationships. 	<ul style="list-style-type: none"> People generally had a positive experience of intimate relationships. Attitudes of staff and family predominantly empowering but some negative views still existed.

Study	Aims	Sample Size	Participant Characteristics	Context	Study design	Qualitative analysis method	Main findings/themes	Conclusions/clinical implications
7. Yacoub & Hall (2008)	To explore the details of sexual knowledge, experiences and attitudes in men with mild ID living in the community and secure hospital settings. To identify areas of unmet need and inform service delivery in these areas.	17	Male. 10 living in community and 7 in a secure hospital. Community participants: aged 29-65 yrs. Secure hospital participants: aged 19-49. None married. Had experience in keeping with project themes. Three involved in lengthy relationships. Two lived with partner.	Recruitment: People using services for PWID. Nominated by health care professionals. Location: England. Data collection: Community participants: 8 own tenancy, 2 residential setting. Interviews continued until the data became saturated.	One semi-structured interview.	Iterative approach to interview process. Inductive analysis technique.	<ul style="list-style-type: none"> • Engagement in unsafe sexual practices despite being aware of the risks. • A shifting of services from paternalistic to more supportive approaches regarding individual's sexual lives and orientation. • Sexual experiences with other men as common. • Being pressurised to have sex with other adults. • Isolation and Loneliness. • Access to pornography prevented. 	<ul style="list-style-type: none"> • Sexual knowledge not leading to safer sexual practices, assertiveness or self-esteem. Interventions to assist translation of knowledge into practice may be helpful. • Sexual vulnerability of men with ID could be addressed by assisting people to meet partners in safe ways.
8. Hollomotz & The Speakup Committee (2008)	Consult with and develop local relationships policy.	Not documented.	Members of self-advocacy group.	Recruitment: not documented. Location: not documented. Data collection: PAC. Consultation about the development of a local relationships policy regarding PWID.	Four focus groups.	Not documented	<ul style="list-style-type: none"> • Being kept in a permanent state of adolescence in relation to sexuality. • Need for personal rights and safety to be balanced. • Importance of being able to make choices about relationships. • Lack of privacy. • Involvement of others in relationships. 	<ul style="list-style-type: none"> • Not possible to stop people being sexual by barring privacy. • Lack of privacy results in people having no choice but to be sexually active in public places. • Need for consistent policy guidelines to enable the right of PWID to privacy and sexual lives to become the norm, not a privilege.

Study	Aims	Sample Size	Participant Characteristics	Context	Study design	Qualitative analysis method	Main findings/themes	Conclusions/clinical implications
9. Kelly <i>et al.</i> (2009)	To provide an understanding of Irish PWIDs' views, experiences and aspirations with respect to sexuality and romantic relationships. To examine the type of assistance they would like from disabilities services.	15.	7 women, 8 men. Age 23-41 years. Service users of disability service.	Recruitment: self-elected from disability services. Location: Midlands, Ireland. Data collection: not documented.	Focus groups and individual interviews (2 participants only). Topic guide used.	In-depth thematic analysis (preliminary results analysed).	<ul style="list-style-type: none"> • Participants knowledge of sexual issues and practices were limited. • Individuals expressed desire for sexual and intimate relationships. • Individuals commonly experienced restrictions around and barriers to relationship. 	<ul style="list-style-type: none"> • Need for comprehensive sex education programmes including components of desire and pleasure. • The perception that intimate relationships are not allowed forces ID individuals to engage in secret relationships leaving them vulnerable to abuse and exploitation. • Findings suggest participants want services to listen to what they say about their needs for assistance in this area and to trust them in relation to forming relationships.
10. Thompson (1994)	Examine experiences of men with ID who have sex in public areas.	19.	Male. Aged 16-67 years old. Varied accommodation. Able to verbally communicate. Able to move independently in community. Identified as taking part in cottaging behaviour.	Recruitment: through sex education service participants attended. Location: Hertfordshire, England. Data collection: Not documented.	Semi-structured interview (only a proportion of participants). Clinical notes.	Not documented.	<ul style="list-style-type: none"> • Hierarchy of power between males who partake in cottaging behaviour. • Absence of pleasure from cottaging. • Cottaging behaviour rarely performed to meet sexual needs. Does meet other needs. • Men who cottage do not always identify themselves as being gay. 	<ul style="list-style-type: none"> • Service providers need to be more sensitive to issues of power in sex between men. • Passivity of men with ID re:relation to safe sex may be related to low value accorded to PWID in society & in turn the value they attribute to their own life. • Need for sex/health educators to be more aware of the reality of the general and sexual lives of PWID.

Study	Aims	Sample Size	Participant Characteristics	Context	Study design	Qualitative analysis method	Main findings/themes	Conclusions/clinical implications
11. Yau <i>et al.</i> (2009)	Examine how PWID respond to and perceive sexuality in Chinese society.	12.	9 female, 3 male. Aged 22-44 years. NGO service users. Mild developmental disabilities. Seven lived with family Five supported hostels. Three married, Nine single.	Recruitment: from NGO services for PWID. Location: Hong Kong, China. Data collection: not documented.	Semi-structured interviews.	Content Analysis.	<ul style="list-style-type: none"> • Striving for normality and social acceptance. • Sex as negative behaviour discouraged by others by restricting the rights and behaviours of PWID. • Struggling with own strategies to meet intimacy needs. 	<ul style="list-style-type: none"> • The pursuit of normality is part of a strong need to get social acceptance. • Participants had a strong desire for sexual expression and intimate relationships. • Appropriately designed sexuality education curriculum is urgently needed alongside the support of family and care givers.

3.4.3 Quality ratings

Table 3.3: Quality assessment ratings

Studies	Quality Criteria										Total Score	Overall Rating
	1	2	3	4	5	6	7	8	9	10		
1. Thompson (2001)	2	0	0	1	1	0	1	0	1	2	8/30	-
2. Fitzgerald & Withers (2011)	3	1	2	2	3	3	3	1	2	3	23/30	++
3. Lesseliers & Van Hove (2002)	3	2	3	3	3	3	3	3	2	3	28/30	++
4. Wheeler (2007)	3	3	3	2	2	2	2	2	2	3	24/30	++
5. Johnson <i>et al.</i> (2002)	3	2	1	1	2	0	2	0	0	1	12/30	-
6. White & Barnitt (2000)	3	2	1	2	2	1	2	1	2	1	17/30	+
7. Yacoub & Hall (2008)	3	2	2	3	2	3	2	1	2	3	23/30	++
8. Hollomotz & The Speakup Committee (2008)	2	2	1	1	1	0	1	1	2	3	14/30	-
9. Kelly <i>et al.</i> (2009)	3	2	2	2	2	1	2	1	1	2	18/30	+
10. Thompson (1994)	2	3	1	2	1	0	1	1	2	2	15/30	+
11. Yau <i>et al.</i> (2009)	3	2	2	2	3	3	2	1	2	2	22/30	+

3= Well addressed, **2=** Adequately addressed, **1=** Poorly addressed, **0=**Not reported/Not applicable

- 1) The presence of clear aims.
- 2) Clarity of the description of research context and setting.
- 3) Appropriate selection of research design.
- 4) Appropriate method and description of sample recruitment and characteristics.
- 5) Appropriate description and method of data collection.
- 6) Systematic description of data analysis.
- 7) Clarity of the description of findings and how this related to the research question.
- 8) Evidence of reflexivity within the research process.
- 9) Identification and addressing of ethical issues.
- 10) Contribution of the research to existing knowledge.

3.5 Critical appraisal of literature

Although the majority of studies demonstrated average to good methodological quality, a variety of methodological limitations were identified, the most prevalent of which related to researcher reflexivity and ethical considerations. In relation to reflexivity no authors adequately reflected on their role within the research process and the impact this may have had upon the data collected. As such the reader is left unsure of the researchers' values, motives and any potential bias, and in turn is unable to consider any alternative interpretations of the data. Ethical considerations were deemed to be adequate in eight studies, poor in two studies, and were completely absent in the remaining article. Ten studies discussed consent and confidentiality, with all but one (Thompson, 1994) describing how these ethical issues were addressed. However, a variety of aspects described by Nind (2008) as being important when conducting research with this population were not considered, including: potential distress; management of disclosure; participants' ability to express their views; participants' feeling under pressure to participate; the research relationship, and withdrawal. Furthermore, ethical approval was only documented in six studies.

Another limitation related to the transparency of methods, which was often poorly documented, with research design and analysis methods rarely being justified. Although it was found that the context surrounding the researcher and participants was described clearly in general, the context of the research projects (where and why the research was being conducted) and documentation of the recruitment process were generally found to be unsatisfactory. Sample characteristics were generally described adequately, however, most

studies did not document any eligibility criteria, nor whether participants met the diagnostic criteria for ID. As such it is possible that individuals who did not have an ID may have participated, which could mean that the studies' findings are unrepresentative. The process of data collection was also found to be absent or unclear in over half of the studies and four studies did not describe an analysis process. Such limitations clearly leave the reader with limited confidence in the findings of these research studies.

Limitations within the results sections of studies were found in over half of the studies. Findings were poorly evidenced due to the limited number of extracts; a lack of transparency in relation to which participants were cited; and presentation of themes across the cohort not being documented. Findings were also found to be poorly presented in half of the studies.

Finally, many studies were limited regarding their consideration of the quality of the research project and its findings. The credibility of findings was rarely discussed as were the weaknesses of the research projects.

3.6 Synthesis of findings

Five main themes were identified from the reviewed studies. These were: ‘A lack of knowledge regarding sexual relationships’; ‘Sexual relationships as restricted and regulated’; ‘Sexual relationships perceived as wrong’; ‘Sexual relationships being desired’; and sex as a negative experience. Themes were identified through the close examination of research findings, which were allocated a descriptive label by the first author and tabulated (see Table 3.4). This process enabled the reviewer to observe the prevalence of themes across the studies. Themes which were presented in less than half of the papers are not included as these were considered to be minor themes. The order in which the themes are discussed relates to the frequency of their presentation across the studies reviewed, with the themes that were presented most frequently reported first. As the studies deemed to have poor methodological quality never represented more than one third of the contributing studies for a theme they were retained within the synthesised results.

Table 3.4: Contribution of individual studies to final themes.

Studies Reviewed	A lack of knowledge regarding sexual relationships	Sexual relationships as restricted and regulated	Sexual relationships perceived as wrong	Sexual relationships being desired	Sex as a negative experience
1. Thompson (2001)	✓			✓	✓
2. Fitzgerald & Withers (2011)	✓	✓	✓		✓
3. Lesseliers & Van Hove (2002)	✓	✓	✓	✓	✓
4. Wheeler (2007)		✓	✓		
5. Johnson <i>et al.</i> (2002)	✓	✓	✓	✓	✓
6. White & Barnitt (2000)	✓	✓			
7. Yacoub & Hall (2008)	✓			✓	
8. Hollomotz & The Speakup Committee. (2008)		✓	✓		
9. Kelly <i>et al.</i> (2009)	✓	✓		✓	
10. Thompson (1994)	✓		✓	✓	✓
11. Yau <i>et al.</i> (2009)	✓	✓	✓	✓	✓

3.6.1 ‘A lack of knowledge regarding sexual relationships’

This theme was present in nine studies. A lack of knowledge was identified in relation to sexual anatomy, the physiological changes within the body during sexual arousal, physical processes such as menstruation and intercourse, pregnancy and childbirth, with some participants being unaware of the link between sex and pregnancy and sexually transmitted diseases. Knowledge acquisition was described in three ways across the studies: through sex education; experience, or opportunistic circumstances such as television programs, magazines or peer discussion. Kelly *et al.* (2009) described how the latter process could result in partial or inconsistent information being acquired. The prevalence of sex education varied across the studies, and it was noted that even when education had been received participants’ knowledge often remained limited (Johnson *et al.*, 2002) or their behaviour did not change (Thompson, 1994; Yacoub & Hall, 2008).

3.6.2 ‘Sexual relationships as restricted and regulated’

Participants across the studies reported having been warned against sex, sex as ‘not being allowed’, or sex being unacceptable outside marriage. This theme was presented in eight studies, all of which found that participants had experienced a lack of support, restrictions, the permission of others being required or decisions being made by others with regards to their intimate relationships. Such involvement was also commonly described in relation to getting married and having children. A belief that individuals would be punished or chastised if they went against the wishes of others or engaged in behaviours such as kissing was also noted. The negative views of others were also conveyed through participants being ignored, or being denied advice.

The influence of others was also found in relation to masturbation and the use of pornography through mechanisms such as a lack of privacy or ongoing monitoring. It is possible that these experiences may have contributed to the development of secrecy surrounding relationships or the level of sexual intimacy within these, which was reported within three studies (Lesseliers & Van Hove, 2002; Johnson *et al.* 2002; Kelly *et al.* 2009). Although a few people were described as being aware of their rights, participants in two studies described having a general acceptance of their position and lack of power (Kelly *et al.* 2009; Yau *et al.* 2009). On the positive side, participants in the Lesseliers & Van Hove (2002) study described that the restrictions and involvement of others were less severe than they had been in the past. Participants in two other studies (Yacoub & Hall, 2008; Kelly *et al.* 2009) also reported that some staff and services reacted positively to their intimate relationship and were supportive of

them. However, these positive reports were in the minority in comparison to the more negative reactions and experiences aforementioned.

3.6.3 ‘Sexual relationships perceived as wrong’

Seven studies made reference to this theme. Sexual relationships were described as problematic, dirty, disgusting, dangerous or associated with illness, which were presented as the perception of the individuals themselves or what they had been told by others. Participants also described experiencing or expecting to experience hostility and negativity from others in relation to sexual relationships and that they should be hidden and not discussed. Interestingly, Yau *et al.* (2009) found that information provided to participants about sexual relationships typically focused on negative aspects such as harassment, exploitation, sexually transmitted diseases and unwanted pregnancy.

3.6.4 ‘Sexual relationships being desired’

Seven papers directly discussed participants’ desire for, or enjoyment of intimate relationships. This was expressed in two ways. Firstly, by participants explicitly describing their want or hope for intimate relationships and continuing to pursue such relationships even though they had been warned against them. Secondly through participant’s discussion or suggestion of other desirable gains, which could be obtained via these relationships. For example, participants associated intimate relationships with companionship, romance, sex, cohabiting and having children. They were also related to being independent and free.

3.6.5 ‘Sex as a negative experience’

This theme was found across six papers. Sexual behaviour within relationships was predominantly described in a negative context with authors observing an absence of pleasure within the narratives of participants. Pain was also strongly associated with sex and negative sexual experiences such as sexual abuse, rape and being coerced into sex were reported to some degree in all six studies. Lesseliers and Van Hove (2002) described how participants desired gentle and tender treatment in sexual encounters but sexual intercourse was perceived to be aggressive and as such was avoided. Thompson (2001) and Lesseliers and Van Hove (2002) also described participant’s general lack of awareness or concern about their partner’s pleasure and pain during sexual interactions.

3.7 Discussion

The review identified eleven papers that reported qualitative research which had investigated the experiences and views of PWID about sexual relationships. These had been conducted in a variety of countries and settings, as such, variation in the ID populations and cultural contexts were observed across the papers reviewed. A synthesis across the studies found five key themes: 'A lack of knowledge regarding sexual relationships'; 'Sexual relationships as restricted and regulated'; 'Sexual relationships perceived as wrong'; 'Sexual relationships being desired'; and 'Sex as a negative experience'.

As highlighted by Craft (1987), participants desired sexual relationships and the positive gains associated with these. However, the majority of the themes indicated that participants remained relatively uneducated regarding sex and sexual relationships. It appeared that the acquisition of information regarding sexual relationships was variable and generally extremely limited with large gaps in knowledge, which could leave individuals vulnerable to misinterpretation and potential exploitation. The association between sex education and PWID ability to keep themselves safe (McCarthy, 1999; Owen *et al.* 2000; Healy *et al.* 2009; Fitzwater & Noonan, 2010; Kitson, 2010) was indicated by the findings of the studies reviewed, with over 80% of papers documenting limited knowledge and over 50% documenting negative sexual experiences. Further the general perception that sex and sexuality were wrong, and something associated with pain rather than with pleasure suggests that, when participants had received information, it may have been skewed and focused upon the more negative aspects of sexuality. Where relationships did occur it seems they continued to be restricted and repressed by

others, which led to some participants becoming secretive regarding relationships. While this may have provided the desired privacy it could also increase participants' vulnerability to exploitation and abuse (Kelly *et al.* 2009).

Positive shifts in attitudes and changes within support services documented by other authors (McCarthy, 1999) were validated by some of the studies. For example, sex education had been provided to a number of participants and some services had responded positively to and supported the intimate relationships of participants, but these experiences were in the minority. It would appear that the stigma, assumptions, ignorance and a lack of autonomy historically associated with the sexual behaviour of PWID (McCarthy, 1999) continued to influence the lives of most of the participants in the studies reviewed. However, synthesised findings of the reviewed papers must be considered with caution due to the methodological limitations of a number of the studies reviewed.

3.7.1 Implications for practices

The findings from this review highlight a number of areas that need to be considered when supporting individuals with ID regarding sexual relationships. The discovery that the majority of participants lacked knowledge about sexual relationships and sexual health indicates the on-going need for effective and positive sex education. Open discussion and the provision of appropriate support should be promoted where possible, in order to counteract any negative impact that rules and restrictions surrounding relationships can have. Attending to the context of individuals with ID and their relationships should be encouraged (Thompson, 2001, McCarthy & Thompson, 2010)

as their life experience, abilities and the societal messages that they have received about sexual relationships are likely to be different to those who support them.

3.7.2 Future Research

The present review indicates the need for more qualitative research of good methodological quality to be conducted in the area of the sexuality and sexual expression of PWID. Specifically research could investigate the factors surrounding the difficulties PWID have translating sex education into practice (Thompson, 1994; Yacoub & Hall, 2008), in order to improve the content and effectiveness of materials. It is possible that investigating the perceptions and experiences of individuals who are struggling to apply such information in real life situations could indicate how sex education may be provided more effectively. Further research could also be conducted with homosexual participants with ID regarding their sexual relationships, as the review did not uncover any research specifically in this area beyond that conducted by Thompson (1994, 2001), which predominantly focused upon men that cottage rather than homosexual relationships. The increasing role of social networking sites and the internet in dating and sexual relationships within the general population (Couch & Liamputtong, 2008) also suggests an area for future research. Particularly as these media were not referred to by any of the studies reviewed when they are being used by this population (Seale & Pockney, 2002) but continue to be an area where little research has been conducted (Seale, 2003). The present review also highlights the need for future research to consider ethical implications and the potential impact of the research fully. They should utilise accepted methods, which are explicitly documented, and authors should reflect on the quality of the research, be reflexive and discuss the context surrounding the project. If these aspects are addressed the qualitative literature base

within this area will aid the development of a clearer understanding of the sexual relationships of PWID.

3.8 Systematic Review References

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4.0 EMPIRICAL STUDY

4.1 Introduction to Empirical Research

The interpersonal relationships of an individual are considered to be an indicator of their quality of life (Brown, 1993; Cummins & Lau, 2003; Richardson & Ritchie, 1989a; Power *et al.*, 2010). Further, social networks and the support that relationships provide have been proposed to be a protective barrier against the stress of life transitions (Romer & Heller, 1983), physical and mental health problems (Heiman, 2001; Newton *et al.*, 1994), as well as acting to increase and sustain the self-esteem and confidence of people with learning disabilities (PWLD, Srivastava, 2001). The systematic review focused upon the sexual relationships of PWLD and outlined the impact that historical and cultural factors had upon this form of relationship. The findings of the review highlighted a variety of factors that continue to influence these relationships, many of which were viewed to have a negative impact upon their development or maintenance. These factors were also found to impact upon an individual's safety in relationships.

Such difficulties are also reflected within wider social networks and interpersonal relationships of PWLD. For example, while social networks may evolve in the context of family, work, education and community (Forrester-Jones & Grant, 1997) and provide an individual with opportunities to develop a variety of different relationships, it has been well documented that the social networks of PWLD are often more restricted than those of the general population (Pockney, 2006; Wiener & Schneider, 2002), which leaves these individuals socially isolated (Department of Health, 2001a; Lafferty, 2008). For example, a large proportion of PWLD do not experience the opportunity to develop work relationships, as they do not work or contact is restricted to the work setting, and thus, social relationships are not formed (Ohtake & Chadsey, 1999). A lack of supportive attitudes, limited opportunities, transport and resources (Brackenridge & McKenzie, 2005; Lafferty, 2008) may also restrict the development of relationships. PWLD are also less likely to experience a parent-child relationship as they are often discouraged from having children and adopt the perception that parenthood is not a realistic option for them (Atkinson & Williams, 1990; McCarthy, 1999). However, even when PWLD do have children it has been found that they are at greater risk of

being removed (Baum & Alexander, 2010). Where people live also influences the relationships they have. Those PWLD who lived with their parents were found to have smaller, predominantly family based social networks, whereas those who lived in community homes were more reliant on paid carers (Krauss, 1992). While many PWLD value relationships with carers, these feelings are not always reciprocated, which may lead to difficulties for both parties (Pockney, 2006).

It is clear that a wide variety of factors influence the social contact and relationships that PWLD experience. There is debate surrounding the underlying cause of the difficulties PWLD encounter regarding interpersonal relationships. Some authors discuss internal factors, such as social skills (Wiener & Schneider, 2002), communication and emotional literacy difficulties (Brackenridge & McKenzie, 2005). When considered in isolation these hold the individual and the difficulties they encounter solely responsible for their limited experience of relationships (Pockney, 2006). Others described external factors founded in society's 'lack of acceptance' (Mills, 1998). This perception highlights the role society plays in the diminished social networks and relationships of PWLD, such as the barriers PWLD face due to society's inability to effectively facilitate their presence and participation in the community. This may be experienced through lacking opportunities for PWLD or negative attitudes (Pockney, 2006).

Attempts have been made to address both internal and external factors, in the hope of promoting better relationships for PWLD. Services have attempted to promote social, communication and emotional literacy skills (Carr *et al.*, 2007) through direct interventions and training programmes, while the adoption of the 'normalisation principle' has targeted external factors through the context of policy recommendations and initiatives to promote social inclusion (Department of Health, 2001a; Scottish Executive, 2000a). However, social skills training has not been found to have a significant impact upon the social competence or relationships of PWLD (Gresham *et al.*, 2011; Moore, 2005), and despite initiatives to promote social inclusion PWLD continue to live socially isolated lives (Lafferty, 2008; Wilson, 2007).

One reason for this failure may be that the relationships of PWLD have most commonly been considered by those other than PWLD themselves. Wilson (2007) reported that

the majority of the research in this area highlighted the power that “parents, carers, service providers and health professionals have...to enable or constrain the development of relationships” (p.22). Historically, the views and perceptions of PWLD about their own social and sexual relationships have seldom been heard. More recently there has been a steady growth in and promotion of self-advocacy (McCarthy, 1999; Sanderson, 1995), service user involvement (Department of Health, 2001a; 2001b; Scottish Executive, 2000b; 2001), emancipatory research (Walmsey, 2001), action research (Bane *et al.*, 2012; Brookes *et al.*, 2012; Johnson *et al.*, 2002), and qualitative research (Knox & Hickson, 2001; Scully, 2008; Wheeler, 2007) in this population. In relation to the latter, a growing body of qualitative research has been conducted with PWLD examining their experiences of friendships (Brackenridge & McKenzie, 2005; Knox & Hickson, 2001; Nunkoosing & John, 1997), going beyond friendship (Lafferty, 2008), sexual relationships (Johnson *et al.*, 2002; Lessilers & Van Hove, 2002; Wheeler, 2007), parenting (Shrewan, 2011), relationships between non-disabled individuals and PWLD (Lutfiyya, 1991; Taylor & Bogdan, 1989), loneliness (McVilly *et al.*, 2006), and the linguistic construction of interpersonal relationships (Wilson, 2007). These developments enable the voices and opinions of PWLD to be heard and promoted, which enables PWLD to begin to influence practice and policy.

4.2 Aims of the current study

The current study aims to build on the existing qualitative research by addressing the gap in the literature regarding PWLD experience and perceptions of close relationships in general. This wider focus has been chosen to provide PWLD with the opportunity to describe relationships that are important to them and how they experience these. The study adopts an exploratory position and as such is not hypothesis driven. However, it is hoped that the process will facilitate the exploration of close relationships for these individuals, which may highlight valued and difficult aspects of interpersonal relationships. This information may offer further insight to PWLD and the people who support them. Such insight may contribute to the development of a shared understanding, from which more appropriate support could be developed and provided surrounding interpersonal relationships.

5.0 METHODOLOGY

This chapter details the research methodology of the study alongside the ethical issues considered by the researcher. Following this the process of ensuring research quality is described.

5.1 Design

The current study aimed to explore and provide a detailed description of the experiences and perceptions of close relationships for individuals who have Learning Disabilities (LD). A qualitative research design which utilised Interpretive Phenomenological Analysis (IPA, Smith *et al.*, 2009; Smith & Eatough, 2007; Smith & Osbourne, 2003) was chosen to do this for the reasons discussed below.

5.1. 1 Qualitative position

Quantitative research aims to identify cause and effect relationships in a large representative sample, which attempt to answer questions relating to the generality of specific phenomena (Yardley, 2000). This form of research is positivist in its epistemological standpoint, tending to focus upon elements and processes that are observable and can be measured (such as depression, anxiety or adaptive behaviour). The isolation of, and focus upon specific aspects or variables has been highlighted as reductionist, especially regarding complex processes such as an individual's experiences. This form of research attempts to explain complex phenomena through the analysis of its fundamental elements. This process is based upon the assumption that the amalgamation of these will be representative of the whole. However, others disagree with such methods, arguing that they limit the level of consideration that can be given to the diversity, range and complexity of the feelings and experiences that are encountered (Nicolson, 1991). It has also been suggested that such research minimises the influence of the social context surrounding an individual. This way of thinking gave rise to the development and growth of the qualitative post-positivist methodologies, which focus upon the meaning and process of an experience for individuals rather than observable behaviour. This form of research does not attempt to obtain generalised findings but rather an in-depth insight into the experiences of individuals and how they

make sense of these. As the focus of this study was to explore participants' views and perceptions in an area where there was limited previous research a qualitative methodology was selected, as this method is more suitable for the preliminary investigation of a complex and diverse area such as feelings, meaning and experience.

5.1.2 Using a qualitative approach with people with a learning disability

Much qualitative research is dependent upon the researcher being able to gain access to the views and experiences of participants through their words, which are then analysed. There has been a long standing assumption that PWLD are unable to participate in qualitative research as this form of data could not be obtained due to the difficulties that many individuals experience in relation to the understanding and expression of language. Although inarticulateness, a concrete frame of reference, unresponsiveness and difficulties with the concept of time have been discussed by researchers within this field (Booth & Booth, 1996; Garbutt *et al.*, 2010; Gilbert, 2004; Munford *et al.*, 2008; Nind, 2008) these challenges can be viewed as limitations of the method rather than the person (Booth & Booth, 1996). In response, a number of researchers (Booth & Booth, 1996; Nind, 2008) have proposed ways in which qualitative research can be modified to overcome the challenges encountered by this population, such as using similar language to the participant, and using more prompts and probes to illicit as much information as possible.

The involvement of this population within qualitative research is advocated by many authors (Munford *et al.*, 2008; Nind, 2008) and is consistent with current policy recommendations, which focus upon service-user involvement in the development of services (e.g. Department of Health, 2001a; 2001b; Scottish Executive, 2000b; 2001). Perhaps as a result there has been an increase in the publication of qualitative research with participants with LD, covering a wide range of areas, such as independent living (Bond & Hurst, 2010), legal rights regarding relationships (Kelly *et al.*, 2009) and physical restraint (Jones & Sternfert-Krose, 2007).

5.1.3 Qualitative approaches

There are a wide variety of qualitative methodologies available to researchers. Those commonly utilised in health-based research studies include: Grounded Theory (GT);

Discourse Analysis (DA), and Interpretive Phenomenological Analysis (IPA). There are many similarities across these approaches, such as the use of semi-structured interviews and the allocation of themes or codes during the analysis process. However, their theoretical standpoints and thus their aims are significantly different (King & Horrocks, 2010). A consideration of each of these approaches is given below.

GT, developed by Glaser & Strauss (1967) is a well-established qualitative method (Willig, 2001) in the social sciences and provides a systematic and sequential framework for implementation (Charmaz, 2003). However, the method is generally associated with the development of a theory from the data, which this study was not aiming to do. Further, as GT was designed to study social processes it was not considered to be an appropriate method for the current research question which is focused upon phenomenology (Willig, 2008).

DA aims to understand how individuals ‘use language to create and enact identities and activities’ (Starks & Brown-Trinidad, 2007, p.1373). Despite the strengths of the method in the critical analysis of the context, DA was not considered appropriate for this study as the methodology focuses on the observable via linguistic behaviour, and the ‘real’ world only as a construction (Reid *et al.*, 2005) rather than the subjective emotional experience of individuals, which is the main focus of this research.

IPA is widely used within health, clinical and social psychology (Smith, 2004). The analysis method was developed by Smith (1996) and ‘is usually concerned with experiences which [are] of particular significance to the person’ (Smith *et al.*, 2009, p.33). This is achieved due to the idiographic nature of the approach and the central positioning of phenomenological aspects within analysis. It is also considered vitally important to consider the cultural context surrounding participants’ experiences. IPA does this by placing experience at the centre of analysis whilst also acknowledging other influential aspects such as historical and cultural factors, social norms and practices (Eatough & Smith, 2006). As the current research project aimed to explore the experiences and perceptions of participants it was considered that the use of IPA would most effectively facilitate this. An additional benefit of the approach was the

clear guidelines described by Smith *et al.* (2009) detailing the practical application of the approach for the novice qualitative researcher.

5.1.4 Interpretive Phenomenological Analysis (IPA)

5.1.4.1 Principles of IPA

There are three core principles within IPA derived from its philosophical foundations: hermeneutics, idiography and phenomenology.

A hermeneutic or an interpretivist approach surrounds the understanding that whilst it is possible to hear another's account of their existence it is not possible to gain full access to their psychological world and experiences. As such, researchers are required to engage in interpretation, which engages IPA researchers in a double hermeneutic, in which 'the participants are trying to make sense of their world, whilst the researcher is trying to make sense of the participants trying to make sense of their world' (Smith & Osborn, 2008, p. 53).

IPA acknowledges that it is impossible for researchers to become detached from their own context, or preconceptions regarding the interpretation, all of which can lead to bias. Thus, the approach emphasises the importance of the researchers' continual critical evaluation and reflection regarding their connection with the data (Smith & Eatough, 2007). It is accepted that any discoveries made using this approach will be a product of the relationship between the researcher and the participant. However, as the researchers' interpretations remain centred on the person and grounded in their words rather than becoming a reflection of the researcher (Smith *et al.*, 2009) the resulting analysis should be plausible to others.

IPA research is also considered to be idiographically positioned. This translates into an intensive and detailed analysis at an individual or small group level, which sits in contrast to the nomothetic methods dominant in psychological research (Larkin *et al.*, 2006). Smith and Eatough (2007) propose that good IPA studies should illustrate the lived experiences of individuals whilst also identifying generic themes from the sample as a whole.

Finally, phenomenology is the way individuals acquire knowledge about the world around them (Willig, 2001). The translation of this principle within IPA is to investigate the meaning that lived experiences hold for individuals (Smith, 1996). By not making assumptions IPA aims to explore how participants make sense of the world through their accounts.

5.1.4.2 Using IPA with people with a learning disability

IPA has increasingly been used with PWLD, to investigate areas such as the experiences of mothers who have lost custody of their children (Baum & Burns, 2007), the experiences of relationships for mothers (Scully, 2009), self-harm in secure services (Brown & Beail, 2009) and the onset of offending behaviour (Isherwood *et al.*, 2007).

5.2 The research context

Yardley (2000) discussed the importance of explicitly detailing the context in which qualitative research is conducted, due to the influence the interaction between the researcher and participant has upon the study. The research was facilitated by People First Scotland (PFS) a nationwide advocacy organisation for individuals with LD. Recruitment took place by an invitation being issued by PFS Development Workers to members at their local PFS meeting (the recruitment method is detailed within section 5.3.5 so this will not be repeated here). Participants did not have any contact with the researcher until the interview day. The researcher had never been involved in PFS, the support services that any of the participants received, nor would she in the foreseeable future. Interviews took place in a setting that was familiar and comfortable for participants, which was chosen by them. The researcher had never been to any of these settings prior to meeting the participants.

Yardley (2000; 2008) also described the importance of the researcher providing relevant background information about his/herself to make the reader aware of any factors that have the potential to influence the objectivity of the researcher. The researcher worked in a learning disability clinical psychology department as a Trainee Clinical Psychologist. The health board in which this department was located did not cover the areas that participants were recruited from. Within this role she worked across a health board area providing clinical psychology services within hospital settings, outpatient clinics and people's homes. Across these settings she worked with individuals, couples, and families as well as facilitating groups. For further information regarding the researcher's context see Appendix L.

5.3 Participants

5.3.1 Method of sampling

The ethos of IPA calls for homogeneity to be established within a sample (Smith *et al.*, 2009). Thus, in common with other research (Brocki & Wearden, 2006), this study used a purposive sampling method, whereby participants were selected based upon criteria relevant to the research project. All participants were Scottish and were active members of PFS. Their membership of this group indicated that they considered themselves to have LD, although no formal diagnostic assessment was carried out due to ethical issues.

5.3.2 Eligibility criteria

The inclusion criteria for the study were that all participants must be adults (aged 18 and over) that were willing to be interviewed independently, who considered themselves to have LD, as indicated by their membership of PFS¹. Participants had to be able to provide informed consent, have English as their first language and expressive language abilities sufficient to allow them to participate in the interview process. Individuals were also required to live in the community, with a maximum of three other adults, which ensured that participants did not live in large group accommodation. Potential participants were excluded if they were currently experiencing severe mental health difficulties or were involved in on-going adult protection procedures or any other proceedings relevant to relationships or sexual activity. This was confirmed through discussions with the PFS Development Worker and the individual.

¹ It is important to note that members of PFS choose to be referred to as having 'learning difficulties' rather than 'learning disabilities' as is commonly used amongst professionals (e.g. Department of Health, 2009; 2001a; BPS, 2000). Their chosen term emphasises that people have the capacity to learn when difficulties in the learning process are overcome (Harris, 1995), which is in line with the social model of disability and also emphasised that these difficulties are not only located within individuals but also within their social environment (Hollomotz & The Speakup Committee, 2008). As such all documents used with participants used the term 'learning difficulties'.

5.3.3 Sample size

As IPA is an idiographic approach it studies small sample sizes to understand specific phenomena in a specific context (Smith *et al.*, 2009). Thus, small sample sizes are considered to be able to provide a sufficient perspective given adequate contextualisation (Smith & Osborn, 2003). In line with this, the suggestion made by Smith *et al.* (2009) that doctoral research utilising IPA should typically conduct between four and ten interviews was followed for this study.

5.3.4 Participant characteristics

Ten people participated (6 men, 4 women). A table summarising participant characteristics and their pseudonyms is presented in Table 5.1.

All participants were members of PFS. Social circumstances varied across participants with three individuals living independently and seven living within a family home. None of the participants were married or lived with partners. Eight participants attended day centre services. One of the participants was employed, one had been employed in the past, and three were doing voluntary work at the time of interview.

Table 5.1: Demographic Information relating to Participants

Participant	Pseudonym	Gender	Age group	Living Arrangement	Number of people living in accommodation
1	Lesley	F	41-50	Own Home	1
2	Lucy	F	31-40	Family Home	3
3	Chloe	F	31-40	Family Home	2
4	Keith	M	51-60	Own Home	1
5	John	M	31-40	Own Home	1
6	Tim	M	41-50	Family Home	3
7	Guy	M	41-50	Family Home	3
8	Oliver	M	51-60	Family Home	3
9	Jane	F	51-60	Family Home	3
10	Ben	M	51-60	Family Home	2

5.3.5 Recruitment

Participants were recruited through PFS: a nationwide group with over 1000 members run by PWLD. As such the project and recruitment process were considered and agreed by the Chairs Committee, which is a group of individuals that have LD and are

members of PFS who chair local group meetings. This was considered important by the researcher given the context that the majority of research conducted with this population is designed and conducted with no consultation with the individuals themselves. Respecting the voice and opinions of these individuals is in line with the service user movement, consultation is also one way of ensuring relevance and quality when developing and evaluating research and services (Allen, 1995). Membership of PFS is also financially accessible², as such it was considered that recruitment from this population would not result in targeting a specific socioeconomic group. Finally, as PFS members are used to advocating their views it was considered that the recruitment of this population would go some way to addressing the concerns surrounding the need for adequate verbal expression skills to participate in qualitative research. This area is discussed in greater detail within section 5.7.2.

Following agreement from the PFS Chairs Committee the recruitment process was initiated. A cover letter (Appendix B), Project Summary Leaflets (Appendix C) and Participant Information Booklets (Appendix D) were provided to PFS Development Workers, who then advertised the invitation to participate to members, alongside an explanation of the project. This took place at PFS group meetings. Project Summary Leaflets (Appendix C) were provided to any members interested in taking part, enabling potential participants to consider involvement between PFS meetings should they wish. The leaflet was designed to be accessible with support and act as a prompt, as invitations to participate were always delivered by Development Workers in person. Those who continued to express an interest were provided with the Participant Information Booklet (Appendix D) and had an opportunity to discuss this with a PFS Development Worker. If individuals still wished to take part the PFS Development Worker provided their contact details to the researcher. Potential participants were then contacted as requested and, if still interested, a convenient time and venue were arranged to meet with the researcher. At this meeting the Participant Information Booklet (Appendix D) was discussed for a second time and the researcher answered any questions about the project. Finally the Consent Form (Appendix E) was discussed,

² £1 for a life time membership

ticked off to indicate the participants' agreement and understanding of each aspect and then signed. A digital recording was made of this discussion and the signing of the document for one participant who had a visual impairment.

Twenty individuals expressed an initial interest in taking part in the study, of which ten finally participated. Of those who did not participate, three lived in large group accommodation, six decided that they were unable or did not want to take part, and one was involved in legal proceedings regarding a close relationship. If potential participants withdrew their interest or it was found that they did not meet eligibility criteria they were thanked for showing initial interest and their contact details were destroyed by the researcher.

5.4 Data collection

5.4.1 Construction of interview schedule

A semi-structured interview schedule (Appendix F) was used to explore participants' experiences. The development of questions was influenced by other qualitative research conducted within the area (Knox & Hickson, 2001; Nunkoosing & John, 1997; White & Barnitt, 2000). The initial schedule was discussed with the research team (consisting of the researcher and their academic and clinical supervisors). As a result the phrasing of questions was altered and a greater range of prompts developed. Members of the team also reconsidered the interview schedule following the pilot interview (see section 5.4.2) to ensure that the questions were appropriate and yielded information relevant to the aims of the study. Six key areas were covered:

1. Understanding and experience of close relationships
2. Understanding of different forms of close relationships
3. Identification of important attributes of close relationships
4. Deciding to enter into close relationships
5. Entering into close relationships
6. The meaning of close relationships.

The schedule was used flexibly as suggested by Smith *et al.* (2009), and at the end of the interview participants were also given the opportunity to raise anything important that they felt had not been covered during the interview.

Questions were developed in line with IPA research methods. As such the questions were deliberately open, and designed to mainly act as cues to facilitate participants to talk about their own thoughts and experiences with minimum constraints from the researcher (Smith, 1995). However, questions were not completely unstructured as general open-ended questions can be problematic for PWLD to respond to (McCarthy, 1999). As such, prompts were also developed for each question area to facilitate discussion. This is also consistent with IPA, which acknowledges the dynamic role researchers play during the interview process. It is possible that prompts may have directed participant's responses in relation to specific areas. Thus, to increase transparency the prompts used during interview have been included within the interview schedule (Appendix F).

5.4.2 Pilot interview

A pilot interview was conducted to assess the feasibility of the interview schedule and interview style of the researcher. The interview was conducted using the format detailed in section 5.4.3. At the end of the interview feedback was sought from the participant regarding the interview process. The interview transcript was also reviewed and discussed by the research team. The feedback from both the participant and research team did not indicate that the interview schedule or interview style of the researcher required significant adjustment, as such, the pilot interview was able to be included within the final data set.

5.4.3 Interview format

It is important that interviews take place in settings that are comfortable and familiar to participants (Smith *et al.*, 2009). As such, six participants requested to be interviewed at day centres and one at a venue in the local community, two opted to be interviewed within their own homes and one at a PFS base. While individual participation is recommended (Smith *et al.*, 2009) one person wished for their PFS Development Worker to be present, however, it was agreed they would be silent during the interview. Interview length ranged from 8-125 minutes, with a mean length of 53 minutes. A second interview was arranged on one occasion, which took place in the same location one week after the first interview. With participants' consent all interviews were digitally recorded. The interviews were semi structured, in order to facilitate rapport and provide participants with the opportunity to think, talk and be heard (Reid *et al.*, 2005) as well as enabling the interviewer to follow up any important or interesting areas raised (Smith, 2004). The researcher's skills as a Trainee Clinical Psychologist were also used to assist the development of rapport and guide the interview. The use of active listening, reflective techniques and frequently summarising information to check its accuracy ensured that participants also felt heard. The importance of participants' views were emphasised at the end of the interview when they were asked if there was anything else that they wanted to discuss regarding the area and to provide their views about the interview as a process. They were also given the opportunity to ask any questions.

5.5 Process of analysis

5.5.1 Transcription

All interviews were recorded using a digital voice recorder. Following interview, participants were allocated a code and once recordings were transferred to a password protected memory stick the original recordings were deleted. With participant consent a paid independent transcription service was used to transcribe eight of the interviews. It is acknowledged that the transcription process is regarded as a key process (Oliver *et al.*, 2005) that acts to immerse the researcher in the data, however, this service was used for all but two interviews as the researcher's ability to transcribe interviews was impaired due to dyslexia. The researcher did transcribe two of the interviews as the participants had severe speech impediments, which would have made transcription by an unfamiliar person difficult. These transcripts were checked by a member of the research team to ensure accuracy. All interviews were transcribed verbatim. The researcher subsequently spent additional time listening to interviews and reading transcripts to ensure that she was fully immersed and connected to the data.

Confidentiality of the data was managed safely through audio files being uploaded and downloaded from an encrypted, password protected server, from which only the researcher and transcriber could access the files. The company also signed a confidentiality agreement (Appendix G). Following transcription, all potentially identifiable information was removed and a pseudonym allocated to each participant. Only anonymised transcripts were used for analysis

5.5.2 Analysis

Within IPA the analytic process is focused upon the double hermeneutic (Smith *et al.* 2009) and is characterised by eventually moving from individual accounts to shared themes. This required the researcher to become emerged and interact with the data. Throughout this process the researcher attempts to remain close to participants' accounts whilst also acknowledging and drawing on their own interpretations. To encourage the interpretive contribution required from the analyst, the researcher kept a reflective diary throughout the data collection and analysis processes as recommended by Smith *et al.* (2009). The data were analysed according to the procedure described by

Smith *et al.* (2009) and recommended for use by novice qualitative researchers (Smith *et al.* 2009). Analysis was conducted on hard copies of transcripts as recommended by Smith *et al.* (2009). A summary of this process is provided in Table 5.2.

Table 5.2: Summary of analytic stages completed

Stage	Description
Stage 1: Reading and re-reading (single case)	The transcript was read and re-read a number of times, enabling the researcher to become immersed in the data. The audio recording was also listened to on several occasions to allow the researcher to recall conversational aspects of the interview. During this stage comments and reflections were noted in the researcher's reflective dairy.
Stage 2: Initial noting (single case)	Exploratory coding was used to analyse each transcript. Coding comprised three forms, descriptive (the content of the account) linguistic (exploring use of specific language within the account) and conceptual comments (raising interpretive questions and interrogative exploration of the account). Initial notes were made in a central column using a colour coded system. (Appendix H)
Stage 3: Developing emergent themes (single case)	Exploring the larger data set (original transcript text and initial notes produced in stage 2) for patterns from which the researcher began to identify emergent themes. These aimed to capture both the participant's experiences and the reflections and interpretation of the researcher (Smith <i>et al.</i> , 2009). Smith <i>et al.</i> (2009) also noted that this process should reduce the volume of detail whilst maintaining the complexity (Appendix H).
Stage 4: Connections across emergent themes (single case)	Connections across emergent themes were explored by the researcher to produce higher level super-ordinate themes. This was done by looking for connections by examining lists of emergent themes (Appendix I) and clustering themes (Whilst clustering themes the researcher attempted to make sense of the connections, through the theoretical or analytical ordering of themes. The researcher found it helpful to print out emergent themes in a list format which were then cut up. This enabled the exploration of patterns by arranging and re-arranging themes spatially. During this stage themes could be removed if they were not well evidenced or they did not fit with the emerging structure. A table of themes was then produced, which listed the themes within each super-ordinate theme. (Appendix J)
Stage 5: Moving on to the next case	Steps 1-4 were repeated for each transcript. In line with the idiographic principles that underpin IPA Smith <i>et al.</i> (2009) highlighted the importance of this process as it allows new themes to emerge from each case, whilst not being influenced by previous analysis findings as far as is possible.
Stage 6: Looking for Patterns across cases	Tables of themes (produced in stage 4) for all transcripts were examined to identify convergence and divergence within the data. A constant iterative process led the movement from individual to overarching themes. A matrix was also generated to assist the development of super-ordinate themes through the identification of recurrent and isolated super-ordinate themes. At this stage the process of analysis and the interpretation of data were also supported by the research team, who met to discuss and reflect on the prominent themes and patterns identified. A table of super-ordinate themes, and the sub-themes contained with these was then produced, which represented the whole participant group (Appendix K).

5.6 Ensuring quality

A number of criteria have been developed to evaluate qualitative research (Elliott *et al.*, 1999; Tracy, 2010; Yardley, 2000; 2008). Yardley (2000, 2008) who is advocated by Smith (2011; Smith *et al.*, 2009) recommends four categories for consideration when assessing quality: ‘Sensitivity to context’, ‘Commitment and Rigor’, ‘Transparency and Coherence’ and ‘Impact and Importance’.

5.6.1 Sensitivity to context

Theoretical sensitivity to context was achieved through consideration of the relevant literature, as described by Smith *et al.* (2009). The process of examining and critiquing literature to justify the study’s rationale also contributed to this awareness. The cultural and political contexts surrounding close relationships for PWLD were also important aspects that were able to be considered through the use of IPA. Further, it was considered important for the research to be conducted with PWLD, rather than those who supported them, which was most common historically.

Sensitivity to context was also acknowledged by considering the inherent power imbalance present between researcher and participant (Brinkman, 2007). The researcher was mindful both that the role of ‘researcher’ and ‘Trainee Clinical Psychologist’ may have triggered pre-conceived ideas about her in the mind of participants, possibly leading to social acquiescence. In an attempt to avoid this, the researcher stressed that there were no right or wrong answers and that she was interested in hearing the participants’ perceptions and experiences. Beyond these factors, ethical issues (as discussed in section 5.7) were also recognised and responded to as described by Tracy (2010).

According to Smith *et al.* (2009) the strongest context to be considered in good IPA research is sensitivity to the data. This was recognised by analysis being grounded in participants’ accounts through verbatim quotes. Themes were also taken back to the participants (see section 8.1.1), which provided an opportunity for discussion, questions, critique, feedback and affirmation (Tracy, 2010). This process also helped the

researcher discover if the participants found the research findings comprehensible and meaningful (Tracy, 2010).

5.6.2 Commitment and rigour

Commitment is described as ‘prolonged engagement with the topic...the development of competence and skill in the methods used, and immersion in the relevant data’ (Yardley, 2000, p. 221). Prolonged engagement was demonstrated by the researcher’s long standing interest in the topic area, having worked for eight years as a clinician with PWLD, and having worked in psychosexual and couple therapy services for two years. Prolonged engagement was also exhibited by her commitment to the data, with the project itself spanning three years. Further in the preparation for the research project a comprehensive review of literature relating to the close relationships of PWLD was also conducted.

In relation to competence and skill, IPA was a new approach for the researcher, however, commitment to the methodology was illustrated by the extensive reading conducted regarding the method and principles underpinning it. The researcher also attended an interactive IPA workshop (facilitated by Paul Flowers), received regular supervision from a member of the research team (who had expertise in qualitative research and had published IPA studies in health research) and attended the Scottish IPA group for peer support. Commitment to the data was also facilitated by IPA’s commitment to idiography, which required the researcher to spend time becoming immersed in the data before the detailed case by case analysis was able to be conducted.

The importance of rigour was also highlighted by Tracy (2010, p. 841) who proposed four questions to assess research projects:

- ***“[Are] there enough data to support the significant claims?”*** As a large volume of rich data were obtained from the interviews, analysis was able to be conducted as described by Smith *et al.* (2009) and the research findings were discussed with a member of the research team and respondents, it was considered that this standard was achieved.
- ***“Did the researcher spend enough time [gathering] interesting and significant data?”*** This is demonstrated by the extensive verbatim quotes from all participants

provided within the analysis, the use of a theme matrix and cyclical checking of themes against individual interviews. All of these steps ensured that super-ordinate themes were firmly grounded within the data and as these themes are felt to provide a new and interesting insight into the area it is felt that this requirement was achieved.

- ***“Is the context of the sample appropriate given the goals of the study?”*** This was achieved by the recruitment of an appropriate homogenous sample (as described by Smith *et al.*, 2009) obtained by adhering to the eligibility criteria (please refer to section 5.3.2 for more details).
- ***“Did the researcher use appropriate procedures in terms of field note style, interviewing practices, and analysis procedures?”*** The answer to this question is addressed within the procedure section (5.4, 5.5) as such it will not be repeated here, however it is considered that the processes followed satisfies the question posed.

5.6.3 Transparency and coherence

Transparency relates to the extent to which the research procedure is disclosed and documented. It also reflects the ability of a third party to understand the researcher’s interpretations, even if it is not the interpretation they would draw themselves. The first aspect is attended to by all aspects of the research process being presented, and where possible evidenced in appendices. The latter was addressed in the use of triangulation with another member of the research team who considered all of the transcripts. Beyond the validation of super-ordinate and emergent themes this process also encouraged discussion which facilitated analysis by the thickening of the data (Tracy, 2010). The areas of contrast raised by this third party led to discussion which also encouraged the researcher to reflect on her position and interpretations.

Coherence represents the consistency between research findings and the theoretical background, research question and methodology chosen. The consistency of the project, that is, adherence to the research question from its development to write up, was maintained by regular discussion with, and supervision from, the research team throughout the research project.

Another element of transparency is self-reflexivity (Tracy, 2010). The researcher was aware of and acknowledged her position and potential influence over the study throughout. As a researcher cannot always be aware of his/her preconceptions in advance (Smith *et al.*, 2009) a reflective diary was kept and field notes were made following every interview. It was hoped that this would assist the researcher to maintain a reflective stance. A reflective commentary is presented in Appendix L to illustrate this process.

5.6.4 Impact and importance

This section explores the contribution that research makes to theoretical knowledge and its ability to be transferred into practice (Tracy, 2010). It is felt that this project is able to offer new insight regarding the close relationships of PWLD, both academically and to those who support these individuals, as the experiences and perceptions of the population are under researched. It is also felt that the project's use of a broad research question enabled participants to discuss relationship forms that were pertinent to them, which has uncovered information about areas commonly ignored within the population, such as the real life experiences of sexuality as opposed to purely focusing on abuse or sex education. The project also allows the audience to consider the social, cultural and political contexts that influenced the participant's relationships, aspects highlighted by Tracy (2010) when considering if a project has made a significant contribution. It is also hoped that sharing the findings with the participants will reinforce their self-advocacy skills, and the awareness that their voices can have an impact whilst also promoting self-efficacy.

Finally, the implication of findings and their potential transferability to practice is discussed within section 8.3.

5.7 Ethical Considerations

A number of potential ethical issues can arise when conducting research with people who have LD. Nind (2008) has provided clear guidelines on how some of these issues can be addressed and this was taken into account when addressing potential ethical issues in the present study.

5.7.1 Informed consent

Research participants with LD are commonly regarded to be a vulnerable group for a variety of reasons including impaired social functioning, social isolation (Dagnan, 2008) and not always understanding that they have the right to withdraw from research (Goldsmith *et al.*, 2008). There are also concerns that they might feel under pressure to consent to participate in research projects to please others due to being more socially acquiescent than other populations (Cameron & Murphy, 2007). Ensuring informed consent is, therefore, a central ethical issue when working with PWLD (Nind, 2008) and is formally recognised within The Adults with Incapacity (Scotland) Act (2000), a key component of which is the presumption that an individual has capacity unless it can be shown otherwise. Gaining consent is also a process rather than a single event (Department of Health, 2001c). In considering this issue, the participants were recruited from a self-advocacy group who are considered to be better placed to make informed choices (Nind, 2008) and were given detailed accessible information, developed with advice from an HPC accredited Speech and Language Therapist, at multiple stages of the recruitment process. It was also made clear that participation was entirely voluntary and that participants could withdraw from the study at any stage. If the researcher had any concerns about the participants' ability to consent she asked questions to verify their understanding of the research and consent process. Finally, all participants were required to sign an accessible Consent Form (Appendix E) to illustrate that they had understood the information contained within the Participant Information Booklet and agreed to take part in the project.

5.7.2 Participant ability to express their views

The participation of PWLD in qualitative research commonly raises concerns in relation to their ability to adequately express their views and opinions verbally, although this has

been rejected by experienced researchers in this area (Brown & Beail, 2009). Despite the challenges of conducting qualitative research with people who experience expressive language difficulties (Nind, 2008; Lloyd *et al.*, 2006) there is a growing body of evidence that PWLD can successfully participate in qualitative interviews on a number of topics, including the experience of personal relationships (Knox & Hickson, 2001; Löfgren-Mårtenson, 2004; Nunkoosing & John, 1997), parenting (Kroese *et al.*, 2002), sex lives (Yacoub & Hall, 2008) service evaluation (Carnaby, 1997; Hagner *et al.*, 1996; Koch *et al.*, 2001) and self-identity (Davies & Jenkins, 2004; Higgins *et al.*, 2002; Meadan & Halle, 2004).

The present study took a number of steps to reduce the potential impact of communication difficulties. Participants were recruited from self-advocacy groups, as these individuals are considered to be more experienced in verbally expressing themselves (Nind, 2008) and to experience less anxiety in doing so (Harris, 2003). It was also made clear to individuals at the start of the interview that the participants should let the researcher know if they felt tired, would like a break, would like to continue the interview on another occasion or would like to end the interview. It was hoped that this would help reduce the impact that fatigue or difficulties in maintaining attention would have upon individuals' communication skills. Beyond this the researcher had experience of working with PWLD, and was able to adapt to the communication needs of the individual. Finally, a pilot interview was conducted and reviewed by the research team to ensure that the interviewer was familiar with the interview process and that the techniques used were beneficial to facilitating communication within this cohort.

5.7.3 Confidentiality: Protection of participant anonymity

Protecting the confidentiality of participants is a fundamental ethical principle and was addressed in the current project by removing potentially identifiable information and allocating each participant a code, which was only accessible to the researcher and was held on a password protected memory stick. Where identifiable information was required to be kept in hard copy e.g. consent forms, this was stored securely at the researcher's base within a locked filing cabinet. Audio recordings of interviews and transcripts were stored electronically on a password protected memory stick. Interviews

were transcribed by a transcription service who had signed a confidentiality agreement (Appendix G) and all identifiable information was subsequently removed from the documents as outlined previously. Information about anonymity, confidentiality and the limits of confidentiality was provided in the Participant Information Booklet (Appendix D).

5.7.4 Minimising potential distress

Although participants were not directly asked any specific questions regarding areas commonly perceived to be sensitive in nature, such as sexual experiences, abuse and bereavement, it was possible that participants may become upset or distressed as a result of the feelings evoked by talking about close relationships. This possibility was highlighted in both the Participant Information Booklet (Appendix D) and Consent Form (Appendix E) and it was noted that support would be offered by the researcher within the interview and on-going support, if required, would be provided by the PFS Development Worker. In addition, if participants became distressed during the interview they were asked if they wished to continue and reminded about available sources of support. At the end of all interviews a short de-brief time was available to allow the participants to discuss their experience of the interview process and any impact that it had upon them.

5.7.5 The researcher relationship

PWLD often lack social networks and relationships with carers and professionals can commonly be perceived as friendships (Pockney, 2006). Thus entering in to a research relationship had the potential to present difficulties as it may extend an individual's social network. To address this, the nature of the research relationship was explicitly discussed prior to interview, the information provided by the researcher included, the role of the researcher, that contact would be short term and that contact would only be made for the purpose of the research study.

5.7.6 Ethical approval

The research proposal and project materials for the study were reviewed and approved by PFS's Chairs Committee in January 2011, and in February 2011 by The University of Edinburgh. Here the project was independently reviewed according to the guidelines

of the School of Health Research Ethics Committee. Comments from both reviews were used to amend and develop several aspects of the project before recruitment commenced. The research proposal was also reviewed by the NHS Medical Research Ethics Team who reported that the project did not need to be considered by a NHS Medical Research Ethics Committee as participants were not being recruited through the NHS and it was not being conducted on NHS property (Appendix M).

6.0 JOURNAL ARTICLE

TITLE.

**‘Touching people in relationships’: A qualitative study of close relationships
for people with learning disabilities.**

Written in accordance with author guidelines for:
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6.1 ABSTRACT

Background. Interpersonal relationships are beneficial for people with learning disabilities, acting as a protective barrier against transition difficulties, social stigma and negative outcomes such as physical and mental health problems. The social networks of people with learning disabilities are, however, often more restricted than those of the general population. There has been very little research exploring the views and experiences of people with learning disabilities about social and sexual relationships.

Aim. To explore the experiences and perceptions of close and sexual relationships in people with learning disabilities.

Design. Exploratory study using a qualitative research design.

Method. Semi-structured interviews were conducted with 10 (6=male 4=female) participants. Data were analysed using Interpretive Phenomenological Analysis.

Results. ‘Touching other people in relationships’ was identified as a super-ordinate theme. The theme was represented by five sub-themes: ‘Is wrong’; ‘Unsafe to talk about’; ‘Suggesting is safe’; ‘No freedom or fun’; and ‘Being touched’. Findings presented are drawn from a larger qualitative study.

Conclusions. Findings highlight the importance of touch and sexual behaviours in the close relationships of participants. Negative perceptions were observed to surround sexual behaviours. Rules and restrictions regarding physical contact were also described.

Relevance to clinical practice. Disseminating these findings may increase awareness of the importance of physical contact in the close relationships of people with learning disabilities and promote positive support arrangements.

6.1.1 KEY WORDS

Learning disability, relationships, experiences, sexuality, qualitative.

6.2 INTRODUCTION

It has been well documented that the social networks of people with learning disabilities (PWLD) are often more restricted than those of the general population (Wiener & Schneider 2002, Pockney 2006). As such PWLD do not have the same opportunities to develop and engage in inter-personal relationships and are often socially isolated (Department of Health 2001, Lafferty 2008). This is concerning as an individual's interpersonal relationships are considered to be protective (Heiman 2001) and an indicator of quality of life (Brown 1993, Cummins & Lau 2003, Power *et al.* 2010).

There is debate surrounding the cause of the difficulties PWLD encounter regarding interpersonal relationships. Some discuss internal factors, such as social skills (Wiener & Schneider 2002), communication and emotional literacy difficulties (McKenzie *et al.* 2001, Brackenridge & McKenzie 2005). Others highlight the role society plays in the diminished social networks and relationships of PWLD. Mills (1998) described society's 'lack of acceptance', experienced by PWLD through lacking opportunities or negative attitudes (Pockney 2006). A combination of these factors has also been proposed, which suggests that PWLD are less able to defend themselves against others' prejudice and preconceptions 'regarding what they think, want and feel' (Lesseliers & Van Hove 2002, p.69). A dominant discourse was identified by Wilson (2007) that PWLD are naïve and dependant and those who support them are knowledgeable and responsible. Potentially this understanding, in combination with a poor ability to defend themselves has contributed to PWLD limited interpersonal relationships. This has occurred as parents and professionals tend to define the boundaries of PWLD

responsibilities, freedom (Lesseliers & Van Hove 2002) and in turn their interpersonal relationships.

Most people with mild or moderate learning disabilities (LD) are capable of, and show, a desire for sex and sexual contact (Craft 1987). However, the false assumptions of others have had a negative influence upon their sexuality and sexual relationships. Historically two contradictory assumptions were particularly influential. The first, that PWLD needed protecting from sexuality as they were considered to be 'eternal children' (McCarthy 1999, Yau *et al.* 2009,) without sexual feelings (Bunyan *et al.* 1986, McCarthy 1999). The second that society needed to be protected against PWLD's pronounced sexuality (Lesselier & Van Hove 2002). These perceptions resulted in the sexual relationships of PWLD being considered controversial and distasteful by many (Bunyan *et al.* 1986). Consequently any interest in sexual relationships or signs of sexual behaviours were repressed, discouraged, or misunderstood (McCarthy 1999). Also, many PWLD were placed in gender segregated institutions, which prevented any heterosexual behaviour.

The adoption of the normalisation principle in the 1970's led to de-institutionalisation and an end to segregated living. It also signified a general shift in attitudes and beliefs. Alongside these changes came the hope and aim of enabling PWLD to live as normal lives as possible, included sexuality (McCarthy 1999). Although services no longer denied or explicitly repressed the sexuality of the people they supported, they developed a role managing the sexuality of PWLD (McCarthy 1999), based upon the preconceptions and views of non-learning disabled individuals. This management did not prevent sexual behaviour, but did discourage it through, rules and restrictions, or a

lack of education and support to reach psychosexual maturity. Such discouragement could be founded in the prejudice of those who directly support them. Alternatively, they may stem from a lack of direction and confidence in the normalisation reforms (Löfgren-Mårtenson 2004). Whilst the principles promoting the rights of sexuality for all have been adopted it is proposed that a lack of consideration regarding how these principles are translated into practice (Johnson *et al.* 2002) has resulted in a lack of support for parents, carers and PWLD (Lafferty 2008, Change 2010, Pownall *et al.* 2012). As such, those directly supporting PWLD are frequently required to generate barriers to sexuality even though the old assumptions have been challenged and institutional barriers have been removed (Löfgren-Mårtenson 2004).

Nevertheless, it has been observed that individuals are starting to take control of their sexual lives (McCarthy & Thompson 1995) and PWLD are more commonly being seen as agents in their own lives (Lessliers *et al.* 2010). This is reflected by an increase in guidelines, policies, and legislation surrounding sexuality (McCarthy & Thompson 1995, Scottish Executive 2000, Department of Health 2009, 2001, Mental Welfare Commission for Scotland 2011), alongside campaigns by the population themselves (Learning Disability Coalition 2012). It has also been documented within the growth of the self-advocacy movement (McCarthy 1999) and an increase in the prevalence of qualitative research, which facilitate the views of PWLD about sexuality and sexual relationships. These developments enable the voices and opinions of PWLD to replace the assumption and opinions of non-disabled individuals that were previously dominant. This change also enables PWLD to begin to influence practice, policy and, most importantly, their own relationships. However, there has been very little research which

has explored the views and experiences of PWLD about their social and sexual relationships (Knox & Hickson, 2001, Wilson 2007, Lafferty 2008).

The current study aims to extend previous research by addressing the gap in the qualitative literature regarding PWLD experiences and perceptions of close relationships in general. This wider focus has been chosen to provide PWLD with the opportunity to describe relationships that are important to them. The study adopts an exploratory position and is not hypothesis driven. However, it is hoped that the process will facilitate the exploration of close relationships for these individuals, which may highlight valued and difficult aspects of interpersonal relationships.

6.3 METHOD

6.3.1 Aim

The research aimed to explore the experiences and perceptions of close relationships in PWLD.

6.3.2 Design

A qualitative design using Interpretive Phenomenological Analysis (IPA, Smith & Osbourne 2003, Smith & Eatough, 2007, Smith *et al.* 2009) was selected to explore participants' views and perceptions in an area where there was limited previous research. IPA was considered more appropriate than other qualitative methods as it is 'concerned with experiences which [are] of particular significance to the person' (Smith *et al.* 2009, p.33) and it acknowledged other influential aspects such as historical and cultural factors, social norms and practices (Eatough & Smith 2006). The interpretative component and transparency of the researcher's context were also aspects that contributed to its selection.

6.3.3 Sample and setting

Participants were recruited in central Scotland, through People First Scotland (PFS), a nationwide advocacy organisation for individuals with LD. It was considered beneficial to recruit from an advocacy organisation as members would be better placed to consent (Nind, 2008) and less likely to acquiesce, having had more experience of sharing their opinions and experiences. Participants self-elected to take part in the study following an invitation to participate provided by PFS Development Workers. As IPA calls for sample homogeneity, participants were recruited using a purposive sampling method.

Inclusion criteria detailed that participants should be adults (aged 18 and over), that were willing to be interviewed independently and considered themselves to have LD, as indicated by their membership of PFS³. Participants had to be able to provide informed consent, have English as their first language and expressive language abilities sufficient to allow them to participate in the interview process. Individuals were also required to live in the community, with a maximum of three other adults, excluding individuals living in large group accommodation. Potential participants were excluded if they were currently experiencing severe mental health difficulties or were involved in on-going adult protection procedures or other proceedings relevant to relationships or sexual activity.

Prior to interview an accessible document detailing the project and procedure was provided and presented by the PFS Development Worker and researcher. This was done to ensure that participants understood what participation would entail, and give them an opportunity to ask questions, following which participants signed a consent form.

Ten participants were recruited. All were white and Scottish. A table summarising participant characteristics is presented in Table 6.1.

³ It is important to note that members of PFS choose to be referred to as having 'learning difficulties' rather than 'learning disabilities' as is commonly used amongst professionals (e.g. Department of Health 2009, 2001, BPS 2000). Their chosen term emphasises that people have the capacity to learn when difficulties in the learning process are overcome (Harris 1995), which is in line with the social model of disability and also emphasised that these difficulties are not only located within individuals but also within their social environment (Hollomotz & The Speakup Committee 2008). As such all documents used with participants used the term 'learning difficulties'.

Table 6.1: Demographic Information relating to Participants

Participant Pseudonym	Gender	Age group	Living Arrangement	Number of adults living in accommodation	Daily activities⁴
Lesley	F	41-50	Own Home	1	VW
Lucy	F	31-40	Family Home	3	DC
Chloe	F	31-40	Family Home	2	DC + VW
Keith	M	51-60	Own Home	1	I + E (past)
John	M	31-40	Own Home	1	I
Tim	M	41-50	Family Home	3	DC + VW
Guy	M	41-50	Family Home	3	DC
Oliver	M	51-60	Family Home	3	DC + E
Jane	F	51-60	Family Home	3	DC
Ben	M	51-60	Family Home	2	VW

6.3.4 Data collection

Interviews were arranged at a time and place of participants' choosing. They were encouraged to select a place they would feel comfortable and would afford privacy. Venues included day centres (n=7), homes (n=2), PFS premises (n=1) and a local community venue (n=1). Interviews were semi structured, facilitated by an interview schedule. This was developed prior to interview in line with IPA methodology, using open questions and prompts as PWLD often find open questions problematic (McCarthy, 1999). Questions surrounded participants' experience of close relationships, what these meant to them and what they valued in close relationships. Interview length ranged from 8-125 minutes (mean=53 mins). All interviews were digitally recorded and transcribed verbatim.

⁴ **Key:** DC – day centre, E - employed, VW – voluntary work, I – spends time independent of services and employment

6.3.5 Data analysis

Transcripts were analysed by the first author using a six stage procedure outline by Smith *et al.* (2009). Exploring the meaning of the experiences (or phenomena) for participants is key but IPA also requires the researcher to interpretively engage with the data (Smith 1996), which was facilitated through a reflective diary and supervision throughout data collection and analysis.

6.3.6 Validity

The analysis process and resulting themes were validated by triangulation with the second author. Participant feedback was also obtained from seven participants who all reported general agreement with the research findings, with one exception. The original theme title, 'Physical Intimacy', was not found to be an accessible phrase for participants and was subsequently changed to the current title, 'Touching people in relationships', suggested by one of the participant.

6.3.7 Ethical considerations

The project and materials were reviewed and approved by PFS's Chairs Committee and The University of Edinburgh, according to the guidelines of the School of Health Research Ethics Committee. A number of ethical issues were addressed through the use of an accessible information booklet. This highlighted that participation in the project was voluntary and that people could withdraw or not answer questions at any time. It also outlined the researcher role, what would occur if participants became distressed, confidentiality procedures and when these might be broken.

6.4 RESULTS

Five super-ordinate themes were identified: ‘Relationships feeling safe and being useful’; ‘Who’s in charge?’; ‘Struggling for an ordinary life’; ‘Hidden feelings’; and ‘Touching people in relationships’. This article describes and explores the latter theme. ‘Touching people in relationships’, was discussed by eight participants. The main areas discussed were, kissing, hugging, holding hands, and sexual behaviours such as sleeping in the same place as their partner, touching other’s private areas and having sex. The researcher observed that these descriptions were often associated with some embarrassment, suggesting that the topic was seen as ‘taboo’. It was considered that the challenges participants’ experienced when discussing the area highlighted its importance. Further, when it was broached it was accompanied by an emotional intensity which had a very powerful impact on the interviewer. Whilst not all respondents talked explicitly about physical touch and intimacy, accounts were sufficiently rich to enable analysis of the content. Five sub-themes were found to relate to touch and physical intimacy: ‘Is wrong’; ‘Unsafe to talk about’; ‘Suggesting is safe’; ‘No freedom or fun’; and ‘Being touched’. Each will be discussed and illustrated using verbatim extracts. The source of extracts are indicated by participants’ pseudonyms. To maintain confidentiality all identifiable information has been changed. Where quotes have been edited for succinctness ellipses (...) indicate omitted material.

6.4.1 ‘Is wrong’

Where touch in the form of sexual behaviours was explicitly discussed it was often considered that such behaviours were seen by others as wrong and a negative thing to do.

“My friend, when I, um, said to my mother, which was quite strange, um, I said to my mother, um, I’m going to invite her to stay with at my house and she turned around and said well if you’re going to do that don’t come back to the house...I phoned her mother to say that, um, I’ll have to ask her to leave because my mother says if I’d if I have her in the house then she’s going to disown me” (Keith)

“Oh, what it was we were, we were taken into school, taken into school by somebody. Somebody said said we were having sex, but we weren’t having sex at all, we were just chatting (...) and they took us down and put us in detention together” (Lucy)

Both Keith and Lucy encountered negative reactions at the mere possibility of sexual behaviours occurring. The participants seemed aware of the potential for further negative judgement during the interview and appear to distance themselves from sexuality, illustrated by Keith’s mislabelling of the couple relationship and Lucy’s presentation of a very acceptable alternative behaviour. Both experiences convey a clear message that sex is a bad thing, also illustrated by Jane who feared others’ reaction to the extent that she did not tell her family about her experience of being raped.

*“I was in hospital for ten days, I was in hospital for ten days
(...) I didn’t tell my family (...) because I was too scared to
tell them.”*

Choosing to conceal the rape suggests that even though sexual intercourse was experienced as the result of a violent act this was perceived as unlikely to lessen the negative views of others. All of the participants’ experiences also convey a powerless position, where others opinions were dominant and must be followed.

6.4.2 ‘Unsafe to talk about’

When circumstances occurred that could be interpreted as times where sexual behaviours may have taken place it was observed that participants were anxious to defend against this possibility. For example, prior to this extract Chloe described that close relationships involved sexual intercourse.

Int. “...have you got any close relationships?”

Chloe. “No [quick response, definite tone]”

Int. “Have you ever had a close relationship in the past?”

*Chloe. “I’ve got a relationship with a boy here (...) but he
doesn’t do nothing like that [clear tone].”*

Chloe makes it very clear that her relationship is non-sexual. The tone and speed of her response to clarify the non-sexual status of her relationship, emphasises the importance of not being misunderstood and suggests that sexual behaviours would not be

acceptable within their relationship. Others were also observed to defend against such interpretations.

“Well I used to go to his house, and he used to invite me to tea, and then I used to go home at night” (Jane)

“So I took her up to the house, two or three hours. We had our dinner, we went and done a couple of things had a chat up the stairs. So that was fine, quite happy.” (Ben)

“Um, she makes me a coffee, I make her a coffee, we have a coffee, we’ll listen to a CD in the bedroom or we’ll go for a lovely walk. We’ll have lunch together” (John)

Spending time together as a couple seems important to all participants. The specification of locations commonly associated with sexual behaviours by Ben and John may be related to a wish to be viewed as adults who have freedom and are trusted to spend time alone in these locations. However, their clarification of these times as non-sexual suggests the importance of defending against such behaviours. This was even observed when participants were able to stay in the same room as their partner overnight.

“And I was quite happy and I used to stay overnights. I used to, first I used to sleep on the floor in the room, she had a

double, a single bed and then her sister got a camp bed and I used to stay overnight.” (Ben)

The significance of staying at his girlfriend’s overnight is clearly conveyed by Ben. However, anxiety that the situation could be misinterpreted is indicated by his clarification that they slept separately. The involvement of others being required for the couple to stay together suggests a public development and external management of the relationship. Further the purchase of a camp bed rather than double bed could be interpreted as others’ residual discomfort and a fear of promoting sexual behaviours in a couple with LD. All of which are likely to have influenced the couple’s behaviour and feelings about sexual behaviours.

6.4.3 ‘Suggesting is safe’

In light of the negative context in which sexual behaviours were viewed, participants often made indirect reference to physical relationships.

Int. “Does that mean your relationship will be different if you get engaged?”

Tim. “It means it will still be the same (...) until Sarah gets used to it (...) until Sarah gets into the relationship.”

“Um, well we, we, we went and cuddled and we kissed each other (...) and then things developed and we’ve always seen each other since.” (John)

Both Tim and John describe that the development of their relationships would lead to a change in the couple's behaviour, but neither openly states what this means. The language and descriptions are akin to what one would expect of adolescents in a relationship where sexual behaviours are going to be experienced for the first time. Such vague descriptions may have been used due to embarrassment at discussing such an intimate area with the interviewer who was a relative stranger. However, it may also have been used to self-protect against potential negative judgments, as hesitation and suggestive language were observed even when participants felt comfortable discussing sex.

“Though with, I did have a brief um affair with May which was, um, that was just a sort of, kind of I don't know what you would. A natural thing.” (Keith)

Here Keith refers sexual behaviour as a 'brief affair', which only implies a sexual experience. Interestingly this term is commonly used in a negative way. Although this is his label, the connotations it implies seem to be defended against later, when he describes the experience as a 'natural thing'. This could reflect an inner conflict between the understanding of sex being wrong and sex being a natural process.

6.4.4 'No freedom or fun'

Throughout the interviews restrictions and negative experiences were strongly associated with sexual behaviours, which seemed to influence the participants' ability, perception of and desire to engage in them. This association could be derived from the behaviour and information provided by others, or from participants own experiences.

“No, I’m not allowed. I can’t (...) they don’t let me (...) it’s just the rules in the place. They don’t let anybody stay overnight.” (John)

The involvement of third parties in relationships limited John’s ability to stay overnight. The power others hold over relationships is clearly conveyed alongside the message that sexuality is wrong, indicated by the blanket rule regarding overnight stays. All of these aspects appear to result in infrequent opportunities to engage in sexual behaviours in complete privacy. The power of others was also observed through the provision of information about sexual relationships. For example, Chloe described receiving teaching about relationships, however, the information she provided indicates that what she was taught or what she had retained had left her with a skewed perception of sexual behaviours within relationships.

Int. “...what do you think close relationships are?”

Chloe. “I think they just make love, ken, man and wife and he just makes love to her (...) it’s all about like, how to make babies and how like that. And how the, how the man puts his penis in the, the lady’s vagina and then makes the egg and then there’s a baby.”

It seems that sexual relationships were understood to only occur within marriage for procreation alone. This perception could be related to some religious understandings of sexuality or information provided to inhibit sexual behaviour. However, the absence of

contraception or pleasure from Chloe's description, suggests the latter is true. This is also supported by sex being presented as male dominant and mechanistic. Conversely, this simplistic presentation could be contributable to expressive language difficulties (Lloyd *et al.* 2006).

Participants' were also influenced by their own negative experiences. Three of the participants had experienced rape or sexual assault, in and outside of relationships.

"...I don't think I'll be ready for that because, um. But I did say to the person that I was raped when I was sixteen and I thought about especially women, um, what they get, well not in the same sort of, kind of way but (...) you have to think about your own safety as well as the other person, because you're doing it (...) and about, um, your responsibilities [laugh] (...) And also, um, about the persons responsibilities..." (Keith)

Keith's experience of rape had focused his attention on risks and potential responsibilities that come with sexual relationships. The impact of rape was also discussed by Jane.

"I had to go to the hospital to get an abortion as well. I had to get rid of it as well and it wasn't, it wasn't my doing, but I just had to get it done (...) because, um. I was surely, I

should say raped. Really bad. Really bad. It was horrible”

(Jane)

It is clear by Jane’s use of language that she did not perceive that she had a choice regarding the abortion. It is possible that the abortion was advised due to the conception occurring within rape. However, Jane later explained that she would never be able to have a child, as such it seems that not having children was the choice of others

“...I can’t have babies or anything like that. I can’t have any more, that’s why I had an abortion because I couldn’t have any.” (Jane)

6.4.5 ‘Being touched’

Half of the participants interviewed made no reference to sexual behaviours, but, it was still made clear that touch was an important aspect of relationships.

Int. “...do you think that it's important to have a close relationship?”

Guy. “Aye”

Int. “What's, what's important about it?”

Guy. “herrr, holding her hand.”

Lucy also described the significant value and meaning of physical contact, relating it to emotional closeness within a relationship.

“I felt closer to William than I did, than I did to Ben (...) because he used to, he used, he used to put his two arms around me(...) instead of just one it was two (...) It made me feel more secure.” (Lucy)

It is possible that the closeness Lucy described is actually physical closeness, and the security described the feeling of being held by another. However, both forms of touch described would also act as a clear sign of intimacy within a relationship to others. Thus, the attachment that these overt symbols represent may also be a key factor in the positive feelings described.

6.5 DISCUSSION

In the current research participants predominantly discussed physical intimacy in the context of boyfriend-girlfriend relationships. Behaviours such as kissing, hugging and holding hands were discussed openly, and touch was described as an important aspect in close relationships. Sexual behaviours were referred to much less frequently and were generally referred to indirectly by participants. This is interesting given that the cohort were all in a stage of life where sexual relationships would typically be developing or established (DeLamater & Friedrich 2002). Previous research regarding close and couple relationships of PWLD also found that sexual behaviours were only spoken about directly by a few participants (Lafferty 2008) or not at all (Wilson 2007). Both authors discussed the impact of cultural constraints upon participants' accounts, which were considered to be influenced by participants' limited opportunities to engage in such behaviours and potential disapproval from others (Lafferty 2008). This is echoed in the current study by the interpretation that participants may have felt unsafe discussing sexual behaviours, which were perceived to be wrong. Wilson (2007) also suggested that participants may feel uncomfortable talking to an unfamiliar person. This was discussed by two participants in the current study during the feedback session. Both described feeling shy talking about the area, but also described that the topic should be kept private and should not be talked about outside of the relationship. These comments could reflect a natural desire for privacy or embarrassment (Change 2010, Bane *et al.* 2012) at discussing such a personal area with a relative stranger. However, they could also reflect the interpretation proposed by the authors and several other researchers (Yau *et al.* 2009, Change 2010, Fitzgerald & Withers 2011) that sexual behaviours are understood to be something that is wrong that should not be spoken

about at all. This was illustrated in the current research by sexual behaviours being concealed and participants defending against being associated with such behaviours.

The basis of negative perceptions surrounding the sexuality of PWLD has also been examined in the literature. Areas discussed have included, sex education that only focused on biological or negative aspects of sexuality (Yau *et al.* 2009, Change 2010), others negative perceptions of sexual behaviours in PWLD (Johnson *et al.* 2002), others negative reactions to couple relationships in PWLD (Lafferty 2008, Thompson 1994), being punished for intimate behaviours (Kelly *et al.* 2009) and negative sexual experiences (Thompson 2001, Yau *et al.* 2009, Fitzgerald & Withers 2010). All of these were described by participants within the current research.

A 'high level of supervision and external control' was described by Wilson (2007, p.110) in relation to couple relationships, which was mirrored by a lack of freedom within the current research. A review of the literature highlights that restrictions and regulations are dominant factors in the couple relationships of PWLD. Participants in several studies described a lack of privacy (Knox & Hickson 2001, Lesseliers & Van Hove 2002, Yacoub & Hall 2008) and being monitored by others (Löfgren-Mårtenson 2004, Lafferty 2008, Kelly *et al.* 2009). Some had been told that sex was not allowed (Wheeler 2007, Change 2010, Fitzgerald & Withers 2011), others were warned against sexual behaviours (White & Barnitt 2000, Yau *et al.* 2009), or told such behaviours were only acceptable in marriage or when living independently (Yau *et al.* 2009), many of which were also presented within the current research. This indicates that living independently in the community or family home does not remove rules and restrictions, which highlights the need for support and guidance for families and staff groups

regarding the translation of the normalisation principals into reality regarding sexual relationships.

Despite the restrictions, barriers, negative perceptions and negative experiences of this population, this research and several other studies (Craft, 1987, Yau *et al.* 2009, Kelly *et al.* 2009) have found that PWLD value and desire touch and sexual behaviours in their close relationships, which clearly highlights its importance in their lives.

6.6 Limitations

The current study has some limitations. IPA recommends a homogenous sample so findings may be more generalisable to that specific population (Smith *et al.* 2009). Although the current sample was generally homogenous variation was present regarding their age, living arrangement and support service. Further, members of PFS do not have to be diagnosed as having a learning disability as defined by the British Psychological Society (2000). While it was not considered to be ethically appropriate to conduct formal diagnostic assessments, this means there may have been some participants who did not have LD within the cohort.

Although measures were taken to ensure that the process of the research project and the limitations of the researcher role were made clear to participants prior to their participation, several individuals made comments which indicated that this information had not been fully comprehended; a common difficulty experienced when conducting research with learning disabled participants (Nind 2008). Although the procedure developed with PFS to manage such situations worked well, the experience highlights the importance of researchers reiterating information and being sensitive to potential misunderstanding and misinterpretation.

Finally, as the study required that participant's expressive language abilities were sufficient to participate in an interview process many members of PFS were excluded from taking part and sharing their experiences. As such future research should seek to develop new strategies to allow individuals with impaired language abilities to participate.

6.7 Relevance to clinical practice

The findings clearly indicate the importance of close relationships and the physical contact that occurs within these. Highlighting the negative impact that rules, restriction and negative attitude have on the close relationships of PWLD may encourage changes in services and supports.

Participants also experienced a lack of support when developing, maintaining and dealing with difficulties within their relationship. As such, services should consider providing training and supervision to staff (Wilson 2007, Lafferty 2008), and materials and supports for parents of PWLD (Change 2010, Pownall 2012). This could change perceptions and increase confidence, which may enable the provision of appropriate support.

This research and other projects (Change 2010, Pownall 2012) found that the information being provided regarding sexual behaviours and relationships is often limited (Change 2010). It may be helpful for services to consider whether their relationship and sex education provisions are sufficient. It is suggested that sex education should focus upon PWLD's right to sexual relationships. They should also present a representative picture of relationships and provide information about desire and pleasure (Kelly *et al.* 2009), as the general message conveyed by participants was that sexual behaviours were wrong and should not be spoken about. Further, as information acquired during sex education is not always translated into practice (Thompson 1994, Yacoub & Hall 2008) the efficacy of supports also needs to be considered.

Finally, the study found that opportunities to develop close relationships and engage in sexual behaviours were limited. As such services need to consider how they can assist PWLD to experience more freedom and increased privacy in relationships.

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6.9 CONTRIBUTIONS

Study design: FS, KB, KMc, EQ; data collection and analysis: FS, KB, KMc, EQ; and manuscript preparation: FS, KB, KMc, EQ.

6.10 CONFLICT OF INTEREST

None.

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7.0 EXTENDED RESULTS

This chapter details the super-ordinate themes that were identified from the data following individual and collective analysis of interviews (as described in section 5.5), excluding those presented in section 6.4. The super-ordinate and sub-themes contained within these (Appendix K) are presented here, and are illustrated using verbatim quotes. The source of quotes is indicated by participant's pseudonyms and page and line numbers. To maintain confidentiality all identifiable information has been changed. Where quotes have been edited for succinctness ellipses (...) indicate omitted material and [] indicates additional information added by the researcher.

7.1 Overview of super-ordinate themes

Five super-ordinate themes were developed from the data: 'Relationships feeling safe and being useful', 'Who's in charge?', 'Struggling for an ordinary life', 'Touching people in relationships' (discussed in section 6.4) and 'Hidden feelings'. Although each theme is distinct they all interconnect, as illustrated in Figure 7.1

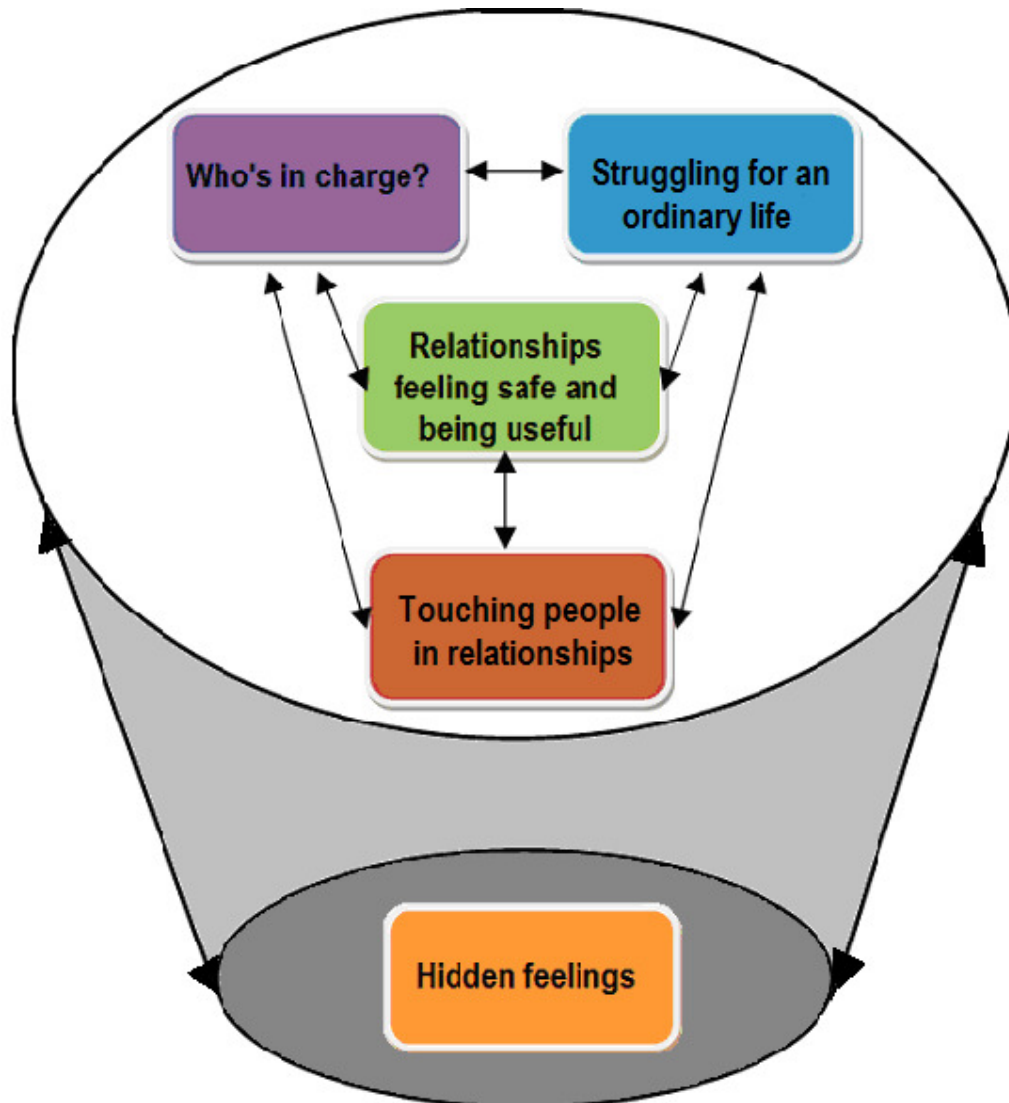
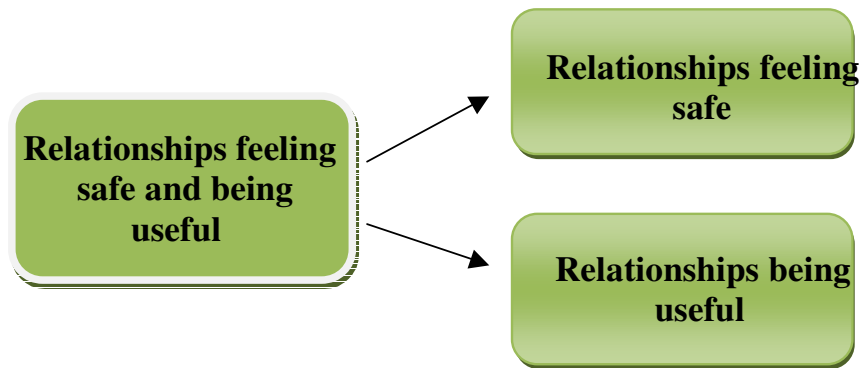


Figure 7.1: Diagrammatic representation of super-ordinate themes and their relationship to each other.

Each theme will be discussed in turn, excluding 'Touching people in relationships' as this was presented in section 6.4. 'Relationships feeling safe and being useful' will be described initially as this was found to be a central to what people hoped for in close relationships. 'Who's in charge?' describes the dynamics and constraints reported within relationships, the impact of which is illustrated in 'Struggling for an ordinary life' and 'Touching people in relationships' (discussed in section 6.5). Finally, 'Hidden feelings' is described. This was presented indirectly throughout the interviews, particularly during the discussion of emotional difficulty. As such it was displayed in all of the aforementioned themes.

7.2 Relationships feeling safe and being useful

This theme was evident across nine interviews. Two key aspects that were found to be important in close relationships: ‘Relationships feeling safe’ and ‘Relationships being useful’.



7.2.1 ‘Relationships feeling safe’

The importance of feeling safe in relationships was a dominant theme for eight and presented by nine of the participants interviewed. Several aspects were found to exist underneath the overarching theme of safety, they were: stability, reliability and trust. Participants conveyed the importance of stability and reliability in a variety of different ways, including staying in regular contact: *“we’re close friends all the time, me and Kirsty. Like she’ll phone me or I’ll phone her, if I need anything”* (Lesley, page 17, lines 580-583) and consistently being there for someone: *“Close relationships, um, um. I would say, um, you stick to somebody that you, you, you, you really really love.”* (John, page 1, lines 5-13).

Stability and reliability were also described in terms of being a regular and stable presence in a geographical space. Oliver described his Father’s regular and stable presence to be the thing he valued most in their relationships: *“well, he kenned, you ken⁵, he (unclear) ken he was there, right. A lot of years, that he liked in the garden.”* (Oliver, page 27, lines 770-774)

⁵ ken is a Scottish word meaning to know or understand.

This may reflect both a practical reliability, in terms of the safety and knowledge of where Oliver felt he could find help and support and a secure attachment to his father, where his stable presence and character acted as emotional comfort itself. This is supported by the comment ‘he kenned’ which implies he was attuned to Oliver’s needs. Although consistency was integral to the close relationships of some participants others found that relationships could be inconsistent yet continue to be experienced as reliable: *“And alright there is days that, she’s got her good days, there is days she’s told me to get lost, and I’ve told her to get lost. But see within the next couple of days we would make up again (...) and that’s partly what it’s all about.”* (Ben, Interview 1, pages 58-59, lines 2137-2146). The equality highlighted within the process, alongside Ben’s confidence that the relationship would be reformed, suggests the relationship was predictable and as such it remained safe. Interestingly, this process, described to be an integral part of the relationship, could be related to the ‘rupture repair’ theory in relationships (Lewis, 2000), which suggests that such processes act to make relationships stronger and more reliable.

Participants also highlighted the importance of stability and reliability through their absence in relationships, which was generally reported to be negative experiences: *“Well Catherine says, Catherine says I’ve not got time to talk to you, I’m busy. And Louisa says I’ll be with you in two minutes Lucy, and in two minutes she’s always there.”* (Lucy, page 56, lines 1886-1891). The contrasting relationships Lucy describes with her key workers clearly demonstrated the significant role that reliability and stability play in relationships feeling safe. Catherine appeared to have been experienced as unreliable and uncaring in the long term, as she did not do as she said and dismissed Lucy as unimportant. In contrast Louisa was experienced as reliable and caring, founded upon her reliable behaviour and consistent provision of support.

The potential loss of a stable other was also described to have a negative impact upon relationships, which could make general life unreliable, unstable, and in turn unsafe.

“I don’t know how it would work if anything happened to my father. I’ve got my father as backup for now, but the only thing is if anything happened to my father I would actually

have to get some people in because, I could cope to a certain extent.” (Ben, Interview 2, pages 30-31, lines 1076-1082)

“I ken, I mean if my mum’s wasn’t there, what’s going to happen to me? [inaudible] (...) I mean, she’s there the now, but probably, I know, you ken the [pause], you know what I ken?” (Oliver, pages 38-41, lines 1078-1183)

Ben and Oliver’s awareness that they would be unable to rely upon their parents in the future resulted in a sense of safety being lost. This is clearly a negative emotional experience, as both men can be seen to defend against difficult emotions indicated in the language they use. Discussing the loss of stability and reliability evoked strong feelings of powerlessness and anxiety. This powerlessness highlights the increased dependence on others that many people in this cohort experience, demonstrating the key roles that others play in creating and maintaining stability in their lives.

The powerful influence others had over feelings of safety was also described in relation to non-exclusive relationships: *“through time everything was okay and all of a sudden (...) she actually says to me that I hadn’t to go back up to the place. And the reason I knew that because when I went up to see her in the Daisy Foundation, um, she was actually, there was somebody coming in and out of her room. On a regular basis. Male (...) he was mucking about, um, doing this and doing that for her (...) So I got rather hurt that way (...) I actually got hurt that way.” (Ben, Interview 1, pages 3-4, lines 82-136).* The relationship had been considered to be reliable and safe prior to this incident, which is described as a shock and change to the previous stability within the relationship. Ben seems to defend against this loss by rising above the non-exclusivity and describing it as dishonourable. However, Ben explicitly described the pain he experienced at the loss of this relationship.

Another way in which safety was described within relationships was through trust. The presence of which was considered to be indicative of a positive relationship. In contrast the absence of trust was described to be a negative emotional experience.

“it’s so wonderful you can trust that person, and that, that person would never hurt your feelings or, I’m sure to God, I know.” (Jane, page 37, 1238-1243)

“and she she just makes things up (...) she just says to me David’s doing this, David’s up here. It’s like alright, in one ear and out the other [laugh] (...) I feel embarrassed at times.” (Lesley, pages 26-27, lines 906-938)

Keith. “I think because Debbie was a bit, what’s the word I’m looking for? Um [tut], no said, um, it’s how she kind of twisted things (...) So I said right well, um, I’m not going to be doing that [inaudible] [laugh] But”

Int. “So it sounds like you decided to end that relationship?”

Keith. “Yeah.” (page 153, lines 5311-5338)

The unreliability of an untrustworthy other seems to limit the safety and depth of the relationship. It appears that Lesley was able to tolerate this unreliability by accepting that she would gain little from their interactions. Keith, by contrast, experienced the lack of trust as too risky, demonstrated by his decision to end the relationship. It is possible that he found the situation more unsafe than Lesley as he later described that others expected him to hold responsibility for the relationship, as the person he was in a relationship with was viewed to be less capable than himself. It is likely that this pressure contributed to the perceived level of risk and the action taken by Keith to end the relationship. As disparity in ability has been described as a common pattern across couples within this population (McCarthy, 1999) such pressure could impact upon many individuals ability to feel safe in relationships.

7.2.2 ‘Relationships being useful’

This theme was discussed by nine participants, for six of whom it was a dominant theme. The importance of the functional role that relationships served was highlighted and tended to relate to practical gains and doing things with others. For Keith, relationships were classified by *“what the person is wanting to get out of the relationship”* (page 123, lines 4266-4267). Interestingly, he describes this process as being one-way, which indicates that the development and form of relationships is not always decided equally within the relationship. The presence of this imbalance was supported by the reports of other participants, who focused upon the importance of personal gains in relationships. For example when asked what were the most positive things about their relationships Chloe said: *“he makes me a cup of tea sometimes”* (page

11, line 374) and Lesley: “*she helps me out a lot and she, when I got this place they all mucked in for [pause]. Did the house up*” (page 43, lines 1499-1503). Their description of tangible gains and practical assistance highlights the significance of personal gain for both participants. However, Lesley’s description also suggests that emotional gains may also be present such as dependability and support for her living independently, indicated by the universal support she received from those around her.

Another important element of close relationships that was commonly presented by participants was sharing activities.

Tim. “*Well we’re going, we’re going to see some, some classes with her (...) like Tae Chi (...) Bum Tums, Action for People (...) and we go to, um, like, um, we go to the market and that (...)*”

Int. “*How do you know that your relationship with Alice is a close one?*”

Tim. “*I don’t know. I think because of the classes we, we [stutter] joined up to.*” (pages 18-19, lines 596-639)

“*Like we’d go do some shopping and whatever. I’d go shopping with her on a Friday a lot (...) Um. Then we’d go out some places sometimes (...) We’d do things.*” (Lesley, pages 2-3, lines 67-85)

Int. “*Who do you think you were closest to out of your mum and dad?*”

Jane. “*My dad [said quickly and loudly] (...) my dad took me holidays. My mum never (...) Like going out places with him, to the pub with him [laugh]*” (pages 114-116, lines 3844-3913)

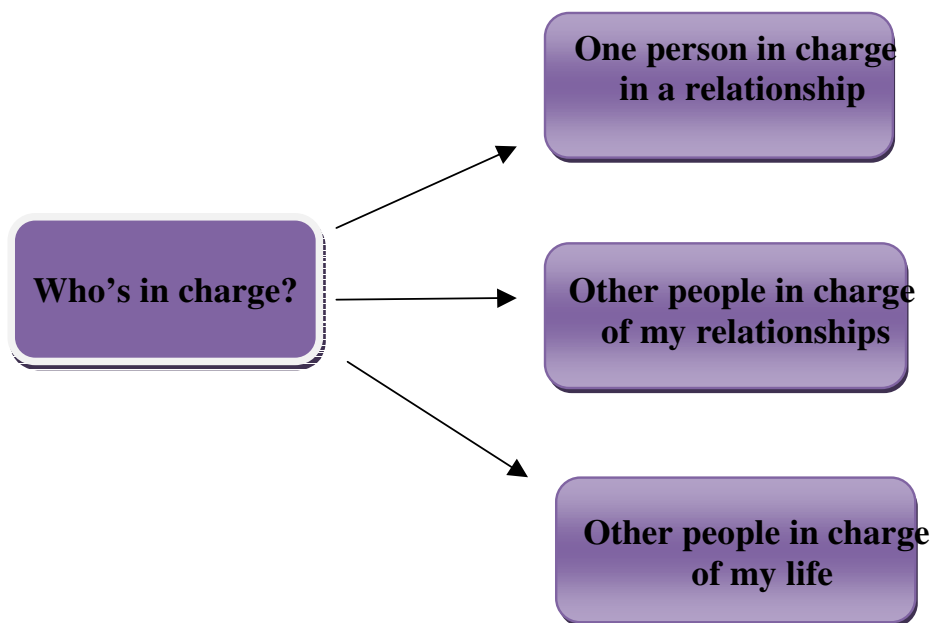
The importance of doing things together is clearly described by Tim, Lesley and Jane. Another common element observed across all of the extracts is the significance of choice and effort, which is likely to represent safety, via an equal investment and dedication to the relationship. It could also be interpreted that the volume of contact, as described by Tim and Lesley, was directly related to the importance that relationships were attributed. Perhaps it was understood that the higher the amount of time spent with another, the closer a relationship. However, it is likely that contact frequency would also be related to safety, reliability and dedication. Finally, it is possible that doing

things with others was highly valued as it represents acceptance, particularly for Jane who indicates that she was included and accepted in all aspects of her father's life, in contrast to the relationship she had with her mother.

To summarise, feeling safe in relationships and them being useful was described as being important in close relationships across the cohort. Safety in relationships was experienced when people knew that others would always be there for them and support them when things were difficult. Trust was also important, which meant individuals felt safe that others would not do anything to hurt them. Where these aspects were present relationships were reported to be good, where they were absent relationships were described as being difficult. Relationships being useful highlighted the importance of getting something good from a relationship. The main things that were described by participants were doing activities or spending time with other people, getting help and getting items such as presents, food or drink. Relationships where individuals gained something were generally viewed positively.

7.3 Who's in charge?

This super-ordinate theme represents the power imbalances that participants faced within relationships. Power imbalances were experienced in three ways, within relationships ('One person in charge in a relationship') others influencing relationships ('Other people in charge of my relationships') and influencing lives ('Other people in charge of my life'). The significance of power imbalances was highlighted further by participant's discussion of equality and feeling in control within relationships, which will also be described.



7.3.1 'One person in charge in a relationship'

Participants often discussed close relationships where there was a significant power imbalance, for example around physical contact: *"begging (unclear) her for a kiss"* (Guy, page 15, line 477), having someone else rely on them: *"I had to do a lot of stuff for her, but another thing I've found with Emily, she was kind of a, clingy."* (Ben, Interview 1, page 6, lines 214-217) or trying to control their behaviour, *"He's on my back all the time (...) I'm not allowed to talk to anybody, he gets a wee bit jealous, he's a wee bit jealous (...) because he's obsessed by me."* (Jane, pages 57-58, lines 1930-

1957). In all of these extracts participants describe being in subordinate positions in relationships, experienced as a lack of agency or powerlessness. Guy was physically disabled and had speech difficulties which were likely to have enhanced his subordinate position within the relationship. However, being in a position of power physically did not always translate across to the relationship dynamic, as illustrated by Ben who felt trapped and overwhelmed by his girlfriend's physical dependence upon him.

The imbalance of power within relationships was not always viewed negatively. However, positive outlooks were most commonly exhibited where participants were in a position of power, such as the caring role described by Oliver when he was asked about positive aspects of his relationship with his mother: "*We're going, going to look after her, aye?*" (pages 32-33, lines 928-930). It is possible that this role gave Oliver a sense of purpose and an opportunity to help others, enabling him to give something back to his mother who had cared for him, which would explain why it was viewed as a positive aspect in their relationship. This sense of role and purpose was also discussed by Ben who described being in a position of power in relationships positively: "*there were only certain people she would talk to (...) and she said to me, she said Ben, she said can you keep an eye on her? She said she's wanting space. I said aye no bother. She said just walk in the room and sit with her, anything Ben. She said are you willing to do that? She said try work as a team with her? I said aye. I said no problems [excitement in voice].*" (Interview 1, pages 66-67, lines 2431-2447). Within this extract Ben illustrates his power by highlighting his unique position and role, which place him as equal or superior to staff members, clearly illustrated in his recollection of a staff member asking him to 'work as a team' with them. This appears to have been a significant and positive experience for him indicated by his tone of voice and the time he took to describe the situation during the interview.

The importance of equality in relationships was also discussed by participants, which was often described through the presence of equality and reciprocity.

"and she's not been very well for a while. But [background noise] I help out with her a lot, and she helps me out with different things." (Lesley, page 37, lines 1261-1265)

“Like make your girlfriend for a cup of coffee and make her tea when she comes in from work (...) and when you come in from work she’ll make you a coffee, she’ll make you tea when you come in from work.” (John, page 39, lines 1107-1116)

The significance of feeling equal or dominant within a relationship was also illustrated by the participants’ desire to feel in control. This was conveyed in their use of language and behaviour when they were placed in subordinate positions.

“Jack wanted to go out with somebody else. I said right Jack if you want to go out with somebody else that’s fine by me. I said I’ll just dump you then. So I dumped him” (Lucy, page 25, lines 827-831)

“And then everything just collapsed when she moved into the Daisy Foundation with that boy...she actually, before I actually split up with her, um, she’d taken a, she’d taken a tantrum.” (Ben, Interview 1, pages 16-17, lines 580-599)

“He didn’t [speaking over Int], he didn’t want, he didn’t want me. So I said to him well you can’t have me or the baby.” (Jane, page 6, lines 180-183)

All three participants were in powerless positions yet their language and presentation remains as though they are the ones in control of the situation. Attempts to regain, or to be seen as regaining control, are made by all participants, which are likely to be self-protective acts. Lucy and Jane also present a very practical account that is devoid of emotion. However, this lack of emotional impact may be presented to further demonstrate their composure and control. In contrast Ben powerfully describes his loss, but he uses defensive language that presents him in a position of superiority, which suggests how he may have come to terms with the circumstance and rendered the situation tolerable.

7.3.2 ‘Other people in charge of my relationships’

This was the most dominant way the ‘Who’s in charge’ theme was presented by participants. The influence that powerful others had over participant’s relationships varied greatly in impact, but individuals tended to accept and comply with this, with no examples of direct challenging being provided throughout the interviews.

- Tim. *"Well, she asked her mother if she could get engaged to me"*
- Int. *"She asked her mother? (...)"*
- Tim. *"Her mothers going to think about it, and she said she's going to answer tomorrow. We'll see what she says." (page 2, lines 53-65)*

Defaulting to parents or carers about making decisions is not uncommon within this cohort, which is likely to stem from the understanding that parents or carers are knowledgeable and responsible, and the people they support are naive and dependant (Wilson, 2007). However, making the decision about becoming engaged to marry seems to sit in direct contrast to such a child-like reliance on others. The level of power held by this parent shocked the interviewer. What was found most shocking was the decision being made by the parent in isolation and that the period of deliberation within which the relationship's future would be decided was readily accepted by Tim. This process suggests that the thoughts and opinions of Tim and his girlfriend were valued far less than their parents, even by themselves. This dependence on others to manage relationships was also found in friendships.

- Lucy. *"I've can't fallen out with Emma now because I've got, got co-ordinators. Me and Emma have got a co-ordinator each. I've got Ian and she's got Jemma and what we do if we fall out we go, we phone Jemma and I phone Ian Emma phones Jemma, because Jemma felt out with her and I phoned Ian and tell him Ian that she's fell out with me (...) and we get a row get a row from from them (...) They make, they help us stay friends (...)"*
- Int. *"So do you, do you think you need them?"*
- Lucy. *"Yeah." (pages 47-59, lines 1583-1651)*

The influence of the coordinators on the relationships was presented as a helpful and a positive process by Lucy. However, underlying this there is a real lack of agency conveyed in her language, alongside the suggestion of a more negative process, indicated by getting 'a row'⁶ when the friends fall out and Lucy's correction from

⁶ To 'get a row' means getting in trouble or being told off in the local dialect.

‘make’ to ‘help’. This raises the question is the support offered always helping or are there occasions when they don’t want to repair their friendship? In relation, coordinators were described to be in positions of power, however, the belief that they were required to maintain the relationship places the friends in an entirely dependant position, which may actually deskill them in the long term.

When participants were viewed to be capable they were sometimes promoted into positions of power. However the consequence of such roles could leave them isolated, as relationships that were formally appropriate were no longer allowed, which resulted in relationships ending:

“I got a warning. I actually got a, and Ellie said I’m not giving you, I’m not giving you a written warning Ben, she said but I’m giving you a warning. She said if it happens again, she said I’ll have to give you a written warning (...) If I, She found me in a relationship with Jenny, an actual relationship. So, what happened ever since, we’ve been very good friends (...) Well we’ve not actually to go about with people in the centre because I’m actually a volunteer” (Ben, Interview 1, pages 55-56, lines 2022-2067)

7.3.3 ‘Other people in charge of my life’

This area is dominated by parental influence over participants’ lives in general, and the power that they held and continued to hold. This sub-theme was dominated by the topic of leaving the family home, discussed by seven participants, six of whom described some form of family involvement in the process. Here Keith discusses his parent’s decision to put him in hospital and Jane describes her mother deciding where she should live.

“Well in my view my mothers and my, my mother and father, um, took the easy option and thought we’ll put him into hospital first to see what they could do and that, its, felt very, What is it? Resentful for, um, because they put me in there and that was me.” (Keith, pages 57-58, lines 1988-1998)

“Well my mum, my mum decided because she named it, she named us off, ken she had, says who is going to stay with so and so and, ken, when we were growing up and that.” (Jane, pages 107-108, lines 3627-3633)

In both of these situations the parents decided where their child would live without consulting the individuals themselves. Both Jane and Keith described that these decisions were based upon what the parents wanted for themselves, and a feeling of powerless was present in both.

Families were also described as preventing individuals from leaving the home: *"I was trying to get one, but said couldn't when dad was there [unclear]. She [mother] said dad wants you there the now. I would of got a house fine, right, and dad, and dad was there, I can't, I can't go anywhere (...) I can't stay with myself (...) I can't cook [unclear], [mumbling] my mum does it for me [laughing]."* (Oliver, pages 42-43, lines 1199-1222). Oliver's language conveys a lack of agency, as again the decisions made were based upon another's needs and wishes, rather than his own. Oliver's account appears to reflect feelings of frustration and the shift from possible to impossible suggests that more recent developments may now be preventing him from leaving the family home. Interestingly he describes dependence on his mother, which could illustrate a belief of being incapable of leaving home, but it may also represent an interdependence (Walmsley, 1993) whose importance may have evolved to fulfil another's needs.

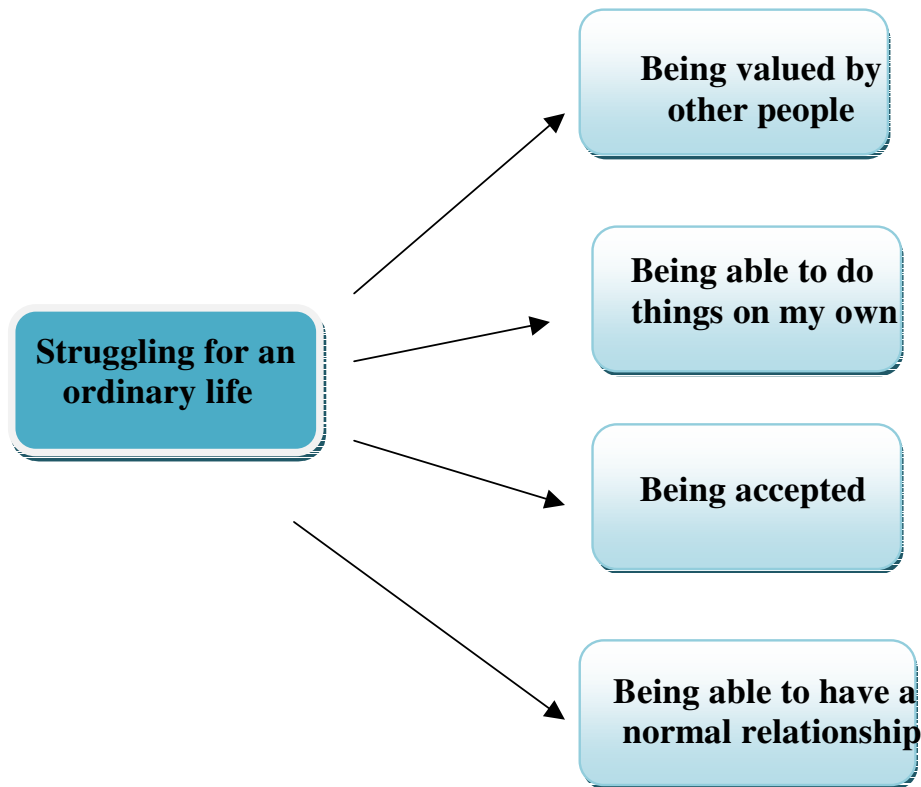
Beyond housing, lifestyle choices were also influenced by family members: *"one year my mother and father was away on holiday and, um, I cleaned everything out of my bank book. My bank book. Not my mother and father's (...) and my mother wasn't very pleased (...) and, she said right you're getting a fiver a night. Once that's finished she said that's up to you. You can do what you want, you can put it in the machine or you can drink it or whatever you want (...) since that happened my mother, my mother and myself didn't really see eye to eye."* (Ben, Interview 2, pages 3-4, lines 102-140). Opportunities to make what may be deemed as poor lifestyle choices were described by several participants as being prevented or resolved by others. It seems important to Ben that he initially emphasised his independence and responsibility by describing that he only spent his own money, which is then contrasted by the behaviour of his mother, who treated him as a dependant and placed strict boundaries around his spending

behaviour. The actions of his mother, which placed her in a position of power, are described to have had a negative impacting upon their relationship.

This theme highlights that participants typically lacked agency in their relationships and lives. Respondents spoke about relationships that were unequal where the person with power could be the participant or the other person in the relationship. People generally desired equal relationships or to be the person in power. However, unequal relationships and being in a subordinate position appeared to be most prevalent for participants and resulted in others often making decisions about what they could and could not do in their relationships and in their lives in general.

7.4 Struggling for an ordinary life

This theme describes four areas that were viewed as fundamental to living an ordinary life by participants: 'Being valued by other people'; 'Being able to do things on my own'; 'Being accepted'; and 'Being able to have a normal relationship'. Nine participants described this theme, but their accounts tended to be polarised, indicating that they struggled to achieve what they perceived to be an ordinary existence.



7.4.1 'Being valued by other people'

The importance of being valued and respected was regularly referred to within the interviews. Often this was raised where an absence of respect had been experienced.

"I feel there's one of two of them that are actually shouting at people (...) another thing I find that they are discussing things that they shouldn't be discussing in front of other people. As you say this is confidential." (Ben, Interview 1, pages 38-39, lines 1363-1370)

Ben described that an absence of confidentiality existed within the culture of the centre he attended, illustrated in the contrast drawn between the confidentiality of the interview and its absence within relationships at the centre. Ben expressed the belief that this lack of privacy was wrong. He also highlighted a lack of respect and disregard for others emotional experience which was also experienced by Jane:

“I had an abortion when I was sixteen, yeah, and it was so scary. I said I couldn’t believe it, that I’ve had this. Why would you let somebody do that to you? [different voice] And my, my, my, one of my auntie said you must have enjoyed it. And that was a terrible thing to say. That was from my auntie.” (page 18, lines 582-593)

A distinct lack of empathy was shown to Jane in relation to her rape and subsequent abortion. Her Aunt’s comment that she chose to have that experience locates Jane in a position of agency, and this, alongside the suggestion that she must have enjoyed the experience demonstrates a lack of respect for Jane. This lack of respect was experienced as something terrible and contrasts with what might be expected from a family member. Jane later spoke directly about the importance of having respect within close relationships: *“talking to me, not down to me (...) treating me with respect, a wee bit of respect. Treating me with a wee bit of respect (...) and I’d treat them with a wee bit of respect.”* (pages 42-44, 1410-1487) Here Jane highlights the importance of equality and reciprocity regarding respect. However, Jane’s language suggests she only expects a limited form of respect from others, which could be related to the lack of respect she had previously experienced.

Other participants described the presence and absence of respect in relation to their key workers.

Lucy. “If I want to talk to Catherine I’ve got to write her a letter to talk to her [laugh] (...) It’s like why is that?”
Int. “How does that make you feel?”
Lucy. “Angry. It takes me ages to write one letter out for Catherine.” (page 62-64, lines 2098-2138)

Lucy experienced barriers that prevented natural communication with her key worker. The implementation of this communication method highlights the power the other held,

and conveys the message that Lucy was not worthy of being spoken to, illustrated by Lucy's question. Again, the absence of respect was described to be a negative emotional experience. In contrast Jane describes respect and positive communication as the reason why her key worker is the person she has the closest relationships with. *"Because she listens, she listens to what I've got to say and that's all I can say. Is my key worker, because she cares more about me [laugh]."* (page 117, lines 3951-3956).

The importance of participant's voices and opinions being heard and respected was also raised in relation to the interview process. When asked how they had found the interview process, Keith and Jane highlighted an absence of opportunities to talk about close relationships.

"[I] think before that nobody has actually asked. We've kind of discussed in a way, in different groups, but not in a great detail, what you are asking me." (Keith, page 170, lines 5911-5915)

"It's been really good. At least, at least, at least, sometimes you don't get a lot of people, um, doesn't take the time to listen." (Jane, page 120, lines 4048-4054)

The experiences described regarding respect and opportunities to talk are likely to influence what individuals are able or feel comfortable expressing to others about relationships. Jane's positive reflections regarding the interview process were also expressed by all of the other participants who took part. Whilst one has to consider the impact the desire to please the interviewer (Kiernan, 1999) may have had upon responses, the consistency of positive comments suggests that someone being interested in their experiences and opinions, taking the time to listen and respecting what they had to say was a positive process.

7.4.2 'Being able to do things on my own'

People valued being able to do things themselves and the importance of role, ability and independence were regularly referred to throughout the interviews.

"see right when, Dad's on the farm there [inaudible] [pause]. There's cattle and on that one aye, cattle and on

them right, [inaudible]. Handle cattle tae, I work I work the farm with him (...) I worked in the farm a long time” (Oliver, pages 12-13, lines 336-349)

Here Oliver was asked about his relationship with his father yet the focus of his description surrounds his father’s job and his own working role. The significance of this aspect is highlighted by an emphasis on his role, which illustrates his abilities and independence. The importance of this for Oliver could be related to dominant assumptions and restrictions regarding independence, which was discussed by other participants:

“There’s a woman that’s in charge because we’re not allowed near cookers and that. She’d done all the cooking and that.” (Ben, Interview 1, page 28, lines 1015-1017)

“the first time I met Ian she was with me, and every time Ian asked me something she answered for me. I was like I’ll answer myself with him [annoyed voice].” (Lucy, page 52, lines 1762-1765)

“Mum and dad are in the house all the time. They never leave me on my own. They are always there with me unless they are going out shopping, but then I, I have to look after the dog (...) I say I’ll look after Millie.” (Lucy, page 58, lines 1936-1945)

In all of these situations Lucy and Ben were assumed to be incapable, as a result they had not been given the opportunity to be independent. This seemed to be frustrating for Lucy, but she was keen to embrace what little independence she could experience, illustrated by her encouraging her parents to go out and leave her with the dog. Both quotes highlight the importance of independence for Lucy.

7.4.3 ‘Being accepted’

The importance of being accepted by others was raised by participants, but this was generally illustrated by situations where participants had experienced rejection.

“well there’s not much chance of me, um, talking to her because she’ll not talk to me, she’ll just say oh get away, (...) Though there, I did have a sort of, kind of a relationship, um,

a long long time ago, but she was a lot younger than me. But because of we, worked in, um, with people with special needs [tut], but my view that there wasn't an issue, we, we seemed to sort of get on [background noise]. But I think because of her other opportunities, better opportunities she sort of, kind of (...) Kind of moved on. But that was very hurtful for me." (Keith, pages 11-12, lines 363-409).

Keith describes two forms of rejection. The first was a general rejection of PWLD by non-learning disabled individuals, who he perceived as dismissing him. He later suggested that those who have an 'understanding' of learning disabilities would not act this way, and Keith goes on to describe his experiences of being in a relationship with such an individual. However, the ending of the relationship implies that he was rejected and replaced by a non-disabled individual. Both forms of rejection are described as negative emotional experiences, but the loss appears to be more intense where an accepting relationship had previously existed. The overall message one receives from this extract is that as a learning disabled individual you are likely to be rejected by non-learning disabled people. Rejection was also experienced in familial relationships: *"And I used to have a close relationship with my Aunt Molly in America [background noise]. When my dad died and I asked if I could go over to see her the next year and she just turned around to me, No [clear strong voice]. Because of my epilepsy (...) I felt hurt."* (Lesley, pages 15-16, lines 518-541). Lesley reported being rejected due to her physical illness, not her learning disability. However, it is possible that this factor was used as an excuse by her aunt, being considered to be a more acceptable and less painful form of rejection. Regardless of its foundation, being rejected based upon an aspect out of one's control was again described to be a negative emotional experience.

7.4.4 'Being able to have normal relationships'

Participants often described what could be perceived to be typical relationship behaviours and situations as desirable or ideal, indicating the importance of having normality in their relationships and lives:

"I would like to get marry [talking over Interviewer], I'd love to get married. But not now [laugh]" (Jane, pages 41-42, lines 1386-1392)

Marriage is a typical progression for couple relationships, but this stage of progression is much rarer in the relationships of learning disabled individuals (McCarthy, 1999). The importance of marriage for Jane was conveyed by its repetition and switch from 'like' to 'love', which emphasises its significance to her, however her comment 'but not the now' coupled with laughter suggests a masking of emotion and self-protective behaviour, which suggests that there may be uncertainty if such a relationship could ever be obtained. When asked what would be important in a partner, Jane replied 'Good looking' (page 41, line 1422) indicating a wish for a stereotypically desirable partner, which alongside marriage would be a common desire that the majority of women are likely to hold (Regan & Berscheid, 1997). John's description of a desired relationship also reflected typical hopes that many have for their relationships and life:

"Aye, having a good, a decent job. A good wage and making each other maybe coffee or tea and talking to each other when you've finished work." (pages 38-39, lines 1096-1101)

However, there may be further meaning behind these 'ordinary' hopes for John. His desire for a 'good' or 'decent job' could reflect the difficulty PWLD find obtaining employment, or his wish to work in a job unsupported. The reference to making coffee, tea and talking to the other after work was described hypothetically, suggesting that such acts were impossible for the couple at that time. However, John had aspirations and plans to make their relationship more normal:

"and I'm putting in for my driving licence, and so I want to save up and get myself a wee Smart car (...) Maybe not a manual, maybe an automatic (...) Um, so I can drive out to see my girlfriend, and I wouldn't have to leave my girlfriend early on a Sunday night" (pages 41-42, lines 1175-1197).

John described a desire for increased freedom in relation to the contact the couple had. The level of freedom desired, though ordinary to most couples, was impossible for them, thus obtaining this would allow them to have a variety of new experiences together. Interestingly John's comments 'maybe not a manual, maybe an automatic' could also highlight an internal struggle to obtain normality, as it suggests an acceptance of his difficulties and the need for compromise to experience ordinary

activities. This non-idealised perception of couple relationships was also presented by Ben:

“We used to, um, socialise and go out maybe down the town, and, um, what. Another thing we used to do is (...) go to her sisters or her mums once a month (...) but her mother could be a bit carnaptious⁷. (Ben, Interview 1, page 13-14, lines 480-516)

Socialising with family was described as a positive factor that maintained the relationship, but as previously observed this contact was described in an honest light describing ordinary not idealised relationships and activities. These would be perceived as mundane activities by most, but to Ben they seemed to represent an independent ordinary relationship. However, the experience of ordinary relationships was contrasted by participants’ descriptions of several barriers that hindered or prevented the development of relationships.

“Relationships with people is, they’re very very rare, because I don’t think they [PWLD] get a chance to sort of, kind of, um, have a relationship, either because of, um, like when, when a youngster, when somebody has a family they sort of do things. Well for me that, I never had the chance.” (Keith, page 1, lines 18-30)

“What we actually had was really good, but because I, in a sense I couldn’t commit myself because of what my mother said. I should have went with my instinct (...) And I mean if I was a sort of, kind of an ordinary, well I am ordinary [clear voice, laugh] person. But I just went with my thingymie.” (Keith, pages 109-110, lines 3790-3809)

“But if it could have worked I would be quite happy to get into a relationship with Jenny, but with me working in here it’d be different. If I was maybe outside, and I may be better outside, that would be different, but with me being a volunteer there is no way.” (Ben, Interview 1, page 60, lines 2193-2199)

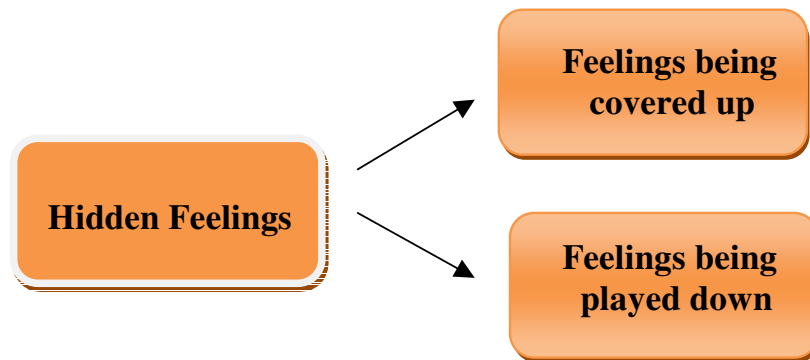
⁷ Scottish word meaning bad tempered or quarrelsome

The involvement of others is highlighted by Ben and Keith in the over protection, rules and restrictions enforced by those in positions of power. There is a sense that relationships and their experiences would have been different had they not had LD, which is clearly illustrated by Keith when he describes what might have occurred if he was 'ordinary'. Keith's comment that he 'never had chance' was likely to be related to his segregation from his family and general society after being admitted to hospital, but it could also imply that relationships were prevented or discouraged as a child. Keith also powerfully illustrates the struggle that participants faced in being ordinary when he vocalised his own inner struggle. His correction and tone implies that he wishes to present a belief that he is ordinary, however his laughter and initial response suggest that inwardly he perceives himself to be different, and unable to follow his instinct in relationships. Ben also highlights an inner struggling in his consideration of what might occur if he no longer worked at the centre, yet there was no suggestion that he would ever leave, which highlights the power that such institutions can hold over individuals.

This theme described participant's desire for an ordinary life, which included: being respected; having independence; being accepted; and being able to have a normal relationship. Being respected meant others would keep their secrets or personal matters private, think about their feelings and listen to what they thought. Relationships where these aspects were absent were described negatively. Participants also liked to do things for themselves such as go out, work, or speak for themselves in meetings. Being free to do these things was valued and being prevented from doing them was disliked. Being accepted by others was a positive experience, however many individuals had encountered rejection due to the difficulties they experienced. Finally, participants desired normality in relationships. This was described as having ordinary relationships where they were free to go and do what they wanted and for this to be accepted by others, as many individuals reported being prevented from having such relationships by other people or by rules.

7.5 Hidden Feelings

Participants commonly described emotions in relation to close relationships. However, these were often presented in subtle, subdued or implied forms rather than being explicitly described. This final super-ordinate theme represents the two dominant ways in which this was expressed: feelings being covered up, and feelings being played down.



7.5.1 'Feelings being covered up'

Strong emotions or emotive experiences were often described but were denied or masked by the participant's presentation.

Oliver. "he had a heart attack and that was it [inaudible], so that's the whole [inaudible] a year [pause], no was it a year [pause, muttering], December the 4th he died I think, I dinna ken."

Int. "Hard to remember?"

Oliver. "But I actually got a, my mum got a fright that day when he died." (page 15, lines 423-431)

Oliver masked the negative emotional impact that the death of his father had upon himself, by shifting the focus away from difficult experiences and focusing on his mother and the date it occurred. This behaviour suggests a distancing from the negative emotions attached to the situation, which was also observed in Jane:

Jane. "Cos my other sisters didn't want me and my other two sisters did (...) So it was awfully, awfully funny."

Int. “Gosh. How did it feel then? When you were saying that your sisters didn’t want you?”
Jane. “Hurt me real bad though. Real sad. Real sad.” (page 107, lines 3634-3648)

The initial presentation of humour was shown to be incongruent to the feelings Jane actually experienced when she was talking directly about her feelings. This initial positive presentation appears to have been used in an attempt to shift the interviewer’s attention away from the negative emotional experience encountered, which was also observed through the use of laughter:

“someone that died that it, I never got over for two years Um. He used to be a father figure for me, for helping me for going out of the hospital, um. And because of his work as a father figure he taught me and he introduced me to his friends or whatever and it was great. But, um, he took his own life (...) Um, and I found him [laugh].” (Keith, pages 29-30, lines 998-1015)

“Since she’s got married I don’t think they’ve got any time for me (...) and I wish they would [laughing].” (Jane, page 90, lines 3038-3045)

The explicit descriptions of emotionally difficult experiences are accompanied by laughter, which is incongruent to the subject matter. Interestingly this laughter occurred at the time participants described the most distressing parts of the experience. Perhaps this laughter acted to contain or reduce the impact of these emotions during their recollection at interview.

7.5.2 ‘Feelings being played down’

Where difficult emotional experiences were raised they were often presented as lacking significance by being minimised or defended against.

“for me it was a bit uptight too, you know I mean, because I was a bit tight that mornin’ ken. An’ the ambulance come, and they get the ambulance to come, and the police come to identify them um, and the boy went in here, and Gav an, he then, he then altered.” (Oliver, pages 24-25, lines 690-699)

Here Oliver described the morning that his father died. Oliver appears to minimise the impact of the emotional experience and distances himself from the experience by using the term ‘them’ rather than referring to his father when recalling the process of identifying the body. Oliver also only refers to his feelings using physical terms, which implies that the expression of emotions may not be considered appropriate or that emotional language was difficult to express verbally. Keith was also observed to minimise his emotional experiences, when he described telling his mother about the death of a friend:

“and my mother said what’s wrong with you? Why are you crying? Um, and I told her. Oh [pause] [background noise], but he’s, It’s only a friend [different voice]. And I was, oh God...but anyway (...) Um, er, that, to me I, It kind of bothered me. Not now but at that time it kind of.” (Keith, pages 38-39, line 1320-1338).

The extract conveys frustration and despair at his mothers behaviour and lack of understanding, which contrast to the minimisation of his feelings. The attempt to shift away from the topic following this comment implies that this had been a difficult interaction and the use of this dismissive term at interview suggests it continued to be a difficult for Keith to discuss. However, Keith’s denial of continuing negative feelings indicates that there may have been an expectation that one should have come to terms with negative feelings over time. Even in the present Keith was observed to defend against negative emotions: *“I get upset, well not, I just say well what’s the point?”* (page 76, lines 2632-2633).

Negative emotions were also occasionally found to be distinctly absent by the interviewer:

“we were alright and then, alright fair enough, there were two or three other people she had her eye on. I didn’t mind that (...) I didn’t mind that at the time. And she said to me, she said right Ben. She said I’m looking for somebody else. I said that’s understandable” (Ben, Interview 1, page 46, lines 1670-1682)

Lesley. "I've got a friend (...) she's married and she's got a family, and I'm not married, I'm single yet [laugh] (...) I mean I would like to have a family but [pause] [sigh] I'm alright. I mean my niece is there, she, I help her and she. And I've got another two nieces and a nephew (...)"

Int. "But you haven't got your own family"

Lesley. "No kids [laugh]"

Int. "How does, I mean how does that feel?"

Lesley. "[laugh] It's alright." (pages 47-49, lines 1607-1694)

Both Ben and Lesley make no direct reference to negative emotions. The use of accepting terms could be perceived to accurately represent their feelings, but both indirectly presented a different picture. Ben may have been trying to present himself in an accepting and emotionally unaffected light, which is illustrated by his use of 'I didn't mind at the time' which suggests that his feelings had been difficult at another point in time. Similarly, Lesley's general presentation and comment 'I would like to have a family but...' indicates that the presented acceptance is not the whole picture. Thus acceptance appears to have been used to mask both Ben and Lesley's true feelings.

Finally, the complex presentation of emotions was not restricted to negative experiences, with the unravelling of positive emotions also being required at times.

Int "Tell me about the important people in your life"

Guy "Arhh, my girl friend (...) J oooo [excited voice] (...)"

Int "How does it make you feel, going out with Jo? Having her as your girlfriend?"

Guy "Alright"

Int "How does it make you feel?"

Guy "Alright" (pages 1-12, lines 23-364)

The importance of this relationship is illustrated by it being the first one Guy described and the excitement in his voice. Thus the later use of 'alright' to describe his feelings about the relationship does not seem to convey the same meaning. Its later repetition indicates that Guy considered that phrase to be the most appropriate way to describe his feelings. However, it is possible that the verbal expression difficulties encountered by Guy limited his ability to describe his emotional experience.

In summary, participants discussed their emotional experiences during interview but explicit descriptions were rare, and they were generally presented in an indirect manner. It is possible that participants were reluctant to share their feelings with the interviewer who was a relative stranger. However, the way in which feelings were presented and the consistency of presentation across the cohort suggested that this was not entirely the case, as several participants had felt comfortable discussing very painful and personal experiences with the interviewer. It appears that participants masked feelings by covering emotions up or playing them down. It seemed that this was done through the use of laughter, redirecting conversations, minimising emotions, presenting the opposite emotion or defending against comments that highlighted the true extent of the feelings experienced.

8.0 DISCUSSION

The aim of the study was to explore the perceptions and experiences of close relationships for PWLD. Analysis of the data revealed five super-ordinate themes: 'Relationships feeling safe and being useful'; 'Who's in charge?'; 'Struggling for an ordinary life'; 'Touching people in relationships'; and 'Hidden feelings'. In this section respondent feedback regarding the findings will be reported followed by each theme being considered in relation to the existing literature, with the exclusion of 'Touching people in relationships' as this was presented in section 6.5. Strengths and limitations of the research method will then be reviewed. Finally the implications for clinical practice and recommendations for future research will be discussed.

8.1 Reflection on themes

8.1.1 Participants' Reflections

Respondent feedback was sought from all of the participants who took part in the project. Seven participants agreed to meet with the researcher, who presented the findings of the research using an accessible document (Appendix N). This was done to enhance participants' understanding and in turn their ability to provide feedback regarding the research findings.

All participants expressed a general agreement with the findings and were happy that they represented their own experiences or the experiences of other PWLD that they knew. There was variation in individual's level of agreement across the themes, which is to be expected given that these were developed from the accounts of ten participants, with different experiences and different perceptions. However, their general agreement indicates that the idiographic focus was not diminished by the authors' interpretations, nor was it lost in the development of the overarching super-ordinate themes, which represented the whole cohort.

One change was made to the findings as a result of the feedback provided. The super-ordinate theme 'Touching people in relationships' was originally entitled 'Physical Intimacy', however, this title did not have any meaning for the participants. The new title was suggested by Ben and was considered to represent the theme well by the researcher, as such this new title was adopted. Some participants were initially unsure about the 'Who's in Charge?' title but after discussing the theme they all agreed that the title was suitable.

It is important to consider the potential power differential that existed within the feedback meeting, and the impact that this may have had upon the feedback provided. For example participants may have felt reluctant to disagree with the author's findings. However, as none of the participants agreed with every aspect of the findings, and they were able to engage in discussions about the suitability of theme titles the research team feels confident that their general agreement with the findings is valid.

8.1.2 Author's Reflections

8.1.2.1 Relationships feeling safe and being useful

The accounts of participants highlighted the importance of close relationships feeling safe and being useful. Safety was portrayed as stability, reliability and trust. These were experienced when others provided consistent and unconditional support, and participants knew that others would not do anything to hurt them. Relationships being useful represents the importance of getting something positive from a relationship, which included tangible items as well as assistance and spending time together. Both of these aspects have also been discussed within the wider literature. The importance of safety was described by Knox and Hickson (2001) who found that both forms of close relationships identified within their study were characterised by a reliable source of support. They highlighted a connection between long-term relationships and relationship satisfaction, which was also discussed by Nunkoosing and John (1997), who found that relationship longevity was one of the factors that characterised close relationships. The importance of this aspect was conveyed by a number of participants within this study, but was most clearly highlighted when long term relationships were threatened, as when Ben and Oliver discussed the potential loss of their parents. Other components such as dependence, commitment, security as well as reliability were described as being important in couple relationships (Bane, 2012; Lafferty, 2008). As such it appears that the significance of 'feeling safe' is experienced by other PWLD.

The importance of function and usefulness in relationships was clearly voiced by Keith and discussed by others within this research project, and this area was found to have strong presence across the wider literature. For example, Brackenridge and McKenzie (2005) investigated the meaning of friendship in PWLD, and identified factors that facilitated friendship from the perspective of PWLD and the staff who supported them. They found that material factors, such as gifts, were more significant to PWLD than staff members. Other research also found that relationships were commonly presented and valued as a means of engaging in social activities and spending time with others (Bane, *et al.*, 2012; Knox & Hickson, 2001; Lafferty, 2008; Pockney, 2006). This area was also presented through the importance of helping in a relationship, as described by Lesley in the current research, and highlighted by participants in several other studies

(Knox & Hickson, 2001; Lafferty, 2008; Nunkoosing & John, 1997; Pockney, 2006). It was proposed by Brackenridge and McKenzie (2005) that behaviours represented by 'relationships being useful' could be valued more by PWLD as they are "concrete and measurable acts" (p. 17) which are easier to be identify as signs of friendship in comparison to the 'feeling safe' behaviours, which are more abstract. This focus could also be related to PWLD relationships being less durable with more limited contact Pockney (2006), which was indicated in the general accounts of several participants within the current research. As such PWLD may aspire for safety in their relationships but in reality only obtain usefulness as an indicator of a close relationship.

From a review of the literature Pockney (2006) reported that 'closeness' or intimacy in relationships was achieved by establishing four components; proximity, disclosure, communication and trust. Proximity is described as close contact, disclosure as the exchange of "privileged knowledge" (p.6), communication as verbal conversation and trust, the exposure of our vulnerabilities to another, thus placing oneself at risk. Participants within the current study described all of these elements, however, the reciprocity described to sit underneath all of these aspects by Pockney (2006) was notably lacking. Although reciprocity was also found to be absent in the several other research projects (Nunkoosing & John, 1997; Thompson 2001; Yau *et al.*, 2009), it still appears to be an important factor in many participants' descriptions of close relationships (Knox & Hickson, 2001; Lafferty, 2008; Nunkoosing & John, 1997). Interestingly, at the foundation of reciprocity is mutual reward, satisfaction and a sense of equality. Pahl (2000) described that achieving balance is necessary for relationships, which is something that has proven difficult to obtain for PWLD. As such it is possible that the variability in the presentation of this aspect is attributable to the variability in power dynamics within the relationships of PWLD, which will be discussed in section 8.1.2.2. However, it could also be viewed that the significance of equality was conveyed by participants within this research through the importance of activities and shared time, as these experiences could provide individuals with shared interests, a sense of commonality (Knox & Hickson, 200; Lafferty, 2008; Wilson, 2007) and reciprocal effort. All of these could help a relationship achieve a more balanced position, which is illustrated within Tim's description of the classes he attended with his friend and his emphasis on the joint effort and equal choice to undertake these activities.

The lack of balance and the safety this provides is also highlighted in sections 8.1.2.2 and 8.1.2.3, within which the negative impact that inequality and a lack of mutuality had upon participants' relationships are discussed.

8.1.2.2 Who's in Charge?

The current study found that participants commonly lacked agency in their relationships and lives, with unequal relationships and being in a subordinate position presenting most dominantly within the relationships described. This was reflected in the wider literature, alongside the impact that those in positions of power can have upon the interpersonal relationships of PWLD. Some authors described this at service level, discussing the negative impact that policy and practice in learning disability services can have upon the development of relationships (Department of Health, 2009; Knox & Hickson, 2001). Others focus on the impact that those supporting PWLD can have, such as Cocks *et al.* (as cited in Knox & Hickson, 2001) who highlighted their ability to actively support, enable or destroy relationships. For example, Shrewan (2011) discussed the influence that powerful others can have upon PWLD decisions and feelings as a parent, similarly participants in Fitzgerald and Withers (2011) reported the restricting effect others had upon the sexual relationships of PWLD. Wilson's (2007) review of the literature also reported the role that parents and health professionals play in restricting or facilitating relationships. As such it seems that the experiences and general feeling of powerlessness reported by the participants of this study are a widespread occurrence within this population.

The historical context surrounding the stigma and the devalued status of PWLD generally and in relation to close relationships was described within section 3.2 and section 4.1, and highlighted the climate surrounding the powerless position of PWLD historically. However, it is important to reflect on how those surrounding PWLD continue to hold positions of power. Treece *et al.* (1999) describe how PWLD often grow up in environments where decisions are frequently made by the caregivers around them. As such, it is less likely that these individuals will challenge the power of others as it is the only context many will have experienced. This acceptance or absence of challenge is exactly what was observed in the cohort interviewed within this study, such

as the behavior displayed by Jane and Oliver when they were told where they would live by their parents.

With regards to the parents of PWLD, Cuskelly (2006) highlighted that even when their sons or daughters become adults they continued to perceive themselves as a parent and not a carer and as such view their roles and responsibilities differently. McConkey and Smyth (2003) described this phenomena manifesting as the continuing need to protect their child and a reluctance to allow them to take risks in relationships and general life, as parents perceived their offspring as vulnerable, are fearful of what could occur, and feel bound to protect them. Concerns about the vulnerability of PWLD are not entirely unwarranted as they are more likely to experience maltreatment than people who do not have disabilities (Horner-Johnson & Drum, 2006). However, Richardson and Richie (1989b) described how some families can become trapped in a vicious circle, where individuals are not given opportunities to experience typical relationships or life situations and learn from these, as such they do not develop life or relationship skills and in turn become more vulnerable and less capable, which encourages an even greater need to protect. It has also been documented that a parent's powerful position can influence PWLD relationships with support staff, as the expectations and opinions of parents are projected onto staff members, which impacts upon the support that is provided regarding the other relationships in the individual's life (Lafferty, 2008). Thus, even if the ethos of a staff team is based upon equality the imbalance of power within the family can change this dynamic. However, over protective behaviour in those who support PWLD has been identified as distinct from parental involvement (Lafferty, 2008). The impact of over protection was illustrated in the accounts of several participants within the current study, such as: John not being allowed to stay at his girlfriend's house due to rules; Keith being threatened with rejection by his mother if his girlfriend stayed over at his house; and Ben being given an allowance due to his spending behaviour.

Participants also described the involvement of others and their dependence upon this in less risky situations, for example Lucy described the role of her coordinator in maintaining her friendship. Although such situations may be emotionally distressing, Lucy's description implies that they were forced to remain friends, which suggests that

staff may have been encouraging the relationship in response to fears regarding limited social networks (see section 4.1 for further information) rather than letting the relationship take a natural course, in which the friends could experience the negative aspects of relationship, which they could learn from (Deeley, 2002). The involvement of others in preventing the natural progression of relationships was also noted by participants in Wilson's (2007) research, who described that they were able to go out on dates but these had to be approved by others. Third party involvement and the need for approval were also reported by participants within the current research as a key aspect that prevented them from living an ordinary life.

8.1.2.3 Struggling for an ordinary life

The desire for an ordinary life was described within the current research as being respected, having independence, being accepted and being able to have a normal relationship. Striving for a normal life was also reported by Yau *et al.* (2009) as being a strong message conveyed by participants. The desire for normality was conveyed in participants' descriptions of couple relationships; in their descriptions of an optimal partner; their own accommodation; and having sufficient money. John also discussed the latter two in the current study. Participants of several studies also described the expectations that relationships would progress to marriage (Knox & Hickson, 2001; Nunkoosing & John, 1997; Yau *et al.*, 2009), which was something that Jane, John and Tim all described they would like in the current research project. The desire for a normal relationship was frequently referred to within the literature, however, this was predominantly in the context of limitations being placed upon relationships by a more powerful other or system, typically a parent, carer or a service facility. Participants in Lafferty's (2008) study reported their right to have couple relationships but also described an awareness that they would have to fight for these. These couples also described staff and professionals hindering the development of couple relationships through the use of rules, restrictions and surveillance, which were also discussed by participants within the current project. Family involvement in couple relationships was also described, such as the need for couples to get family consent (Morentin *et al.*, 2008) or families becoming too involved in couple relationships (White & Barnitt, 2000). This was an aspect highlighted by Tim when he described that his girlfriend's mother was deciding if they could get engaged.

Another factor that was reported within the literature, which reflected the experience of participants within the current study, was a lack of privacy (Hollomotz & the Speakup Committee, 2008; Knox & Hickson, 2001), discussed by John in this project. Participants in other studies also discussed having children (Knox & Hickson, 2001), however, in the current study none of the participants had children nor did they express any hope of having them in the future. This is interesting as it sits in contrast to the other areas in which participants were struggling to be 'ordinary', given the cohort were at parenting age, unless an individual had made a conscious decision not to have children, or were unable to. Such a decision was only discussed by Jane in relation to the abortion she experienced after being raped, but even here it did not seem like this had been her decision alone. An absence of accounts regarding PWLD as parents was also found by Wilson (2007).

The right to have normal relationships alongside the right to be accepted, valued and have independence have all been highlighted and discussed in government publications and initiatives as areas that need to be improved and supported (Department of Health, 2001a; 2009; Scottish Executive, 2000a). These aspects have also been reported in documents produced by service user groups as areas of difficulty for PWLD which need addressing (Department of Health, 2001; Disability Coalition, 2012). Wilson (2007) suggested that the rhetoric driving policies and services regarding the rights of PWLD to all forms of relationships was having little impact in practice. The struggle to achieve 'ordinary relationships' and the absence of the parent-child relationships highlighted within the current research and wider qualitative literature, adds further weight to this proposal. The limited impact of policies was also highlighted by Lafferty (2008) in relation to societal behaviour. She found that societal prejudice and judgments continued to play an influential role on the close relationships of the couples she interviewed, and the level of respect that they were shown as individuals. All of these elements suggest that an absence of acceptance and being valued as people is also experienced beyond the participants interviewed in this research study. Likewise, the wider research also indicates that the areas identified within the 'Struggling for an ordinary life' theme are salient for PWLD at the present time.

8.1.2.4 Hidden Feelings

Participants' descriptions of their emotional experience during interviews were commonly presented in an indirect manner, with explicit descriptions rarely occurring. Feelings appeared to be masked by being covered up or played down, through the use of laughter, redirecting conversations, minimising emotions, presenting the opposite emotion or defending against comments, which seemed to highlight the true extent of the feelings experienced. It is well established that PWLD commonly experience difficulties in interpersonal and emotional functioning (McKenzie *et al.*, 2001 p.26), and they are considered to be less capable of expressing their feelings (Grant *et al.*, 2010). Grant *et al.* (2010) reported that this can manifest as the reluctance or absence of expressed positive and negative emotions, both of which were presented by participants within the current research. As such, it is possible that participants' difficulties to identify the emotional state of themselves and others (Rojahn *et al.*, 1995a; 1995b; Walz & Benson, 1996) underpinned the 'hidden feelings' observed.

Another factor that may have played a role in this area was impairments in speech and language abilities that are typically associated with intellectual disability (Carr *et al.*, 2007). Tim, Oliver and Guy experience speech impediments, of which Guy's were significant. It is possible that this difficulty contributed to their limited emotional expression, however this theme was present across the entire cohort, which suggests speech difficulties cannot be totally accountable for the presentation of emotion in this way.

Another possibility is that presenting in this manner enabled participants to convey what felt safe and appropriate for them at the time of interview. As highlighted by Charmaz (1995) people may not want to and do not have to disclose everything about themselves. Thus, this presentation may represent participants' desire to keep particular experiences private and were a reaction against the intrusion of the researcher. It could also be in response to painful feelings that emerged during the interview. Ekman and Friesman (1975) introduced the term 'display rules', which are described as being learnt when individuals are young as a means of managing specific emotions in specific situations. It has been described that these display rules enable an individual to control their behaviour in accordance with their knowledge of what is appropriate regarding

emotional expression in a particular context (Zaalberg *et al.*, 2004), which are influenced by personal identity and pro-social factors. For example, Zeman and Garber (1996) found that childrens' decision to express emotion were influenced by the type of audience. The control of emotion was found to be used significantly more in the presence of peers in comparison to when they were with their family or alone, particularly in relation to negative emotions. As such it is possible that the researcher's presence as a stranger may have induced heightened emotional control in the participants of the current study. This 'masking' is also discussed within the context of display rules, described as replacing a felt emotion with an unfelt emotion, which was observed across the participant group through the use of laughter.

Laughter and humour have been discussed in the literature as means of inhibiting or facilitating conversation and an acceptable means of changing the direction of conversation or shifting another's attention if one does not wish to continue with the topic being discussed (Foot, 1997). This is interesting given the frequent displays of laughter when participants recounted difficult emotional experiences. Laughter has also been described to reduce high levels of unpleasant emotions, as it acts to release heightened arousal and dissipate difficult feelings (Foot, 1997). This may have been another reason why laughter was displayed by participants when emotionally painful situations were being described.

8.1.2.5 Summary of author's reflections

Consideration of the wider literature in relation to the themes identified within the current research reveals that the aspects raised by the participants regarding safety, usefulness, power, control, respect, acceptance, independence, and physical intimacy are all significant elements in the close relationships of PWLD. The presence of hidden feelings is also well documented in relation to the emotional literacy difficulties the population often experiences, and the impact that an interview process can have upon participants' accounts. As such it is considered that the findings of the research are congruent to existing literature and contribute to the evidence base by highlighting the significance of these aspects for PWLD across many forms of close relationship.

8.2 Methodological Critique

8.2.1 Strengths

The study had a number of strengths. Firstly, as far as the researcher is aware this is the first piece of qualitative research conducted in Scotland that has explored the social and sexual relationships of PWLD from their perspective. However, the findings also contribute to previous research, which highlight that expressive language difficulties do not appear to have a significant impact upon the data gathered (McCorkell, 2011; Yacob & Hall, 2008). Although speech difficulties were experienced by several participants this difficulty was overcome by allowing more time to conduct the interviews. The researcher also asked for confirmation of her understanding regarding the accounts participants provided. A number of other strategies were also utilised to assist participation, such as accessible documents (Appendix D, L). Using these strategies participants were found to express their views and reflect upon their experiences, which in turn provided rich accounts. As such, the research supports the work of Nind (2008) and Lloyd *et al.* (2006) who describe that qualitative research with this population can be challenging but it is achievable by being creative and adapting the process to make the method accessible.

Another area of strength is the transparency of the researcher's context and experience throughout the research process. This is also considered to be a key factor in the validity of this research project. There is always a risk when researchers engage in projects, particularly within their own area of practice, that their own preconceptions or motives could influence the research (Kiernan, 1999). Although these tensions were apparent to the researcher throughout the project, the use of a reflective diary and in turn the provision of a reflective commentary (Appendix L) will allow the reader to identify any areas where the researcher may have influenced the project.

Finally, the credibility of the researcher's interpretations are also considered to be robust, as the process was assisted through regular discussions with the research team and by obtaining feedback on the research findings from the participants. Sharing findings of qualitative research with participants has been highlighted as a challenging area (Nind, 2008), addressed within this project by findings being fed back using an

accessible document (Appendix N). Both processes led to aspects of the project being revised, which illustrates their value and role in assisting the researcher to maintain a more reflexive position. It is believed that participants influence on the project also enhances its validity.

8.2.2. Limitations

There were various limitations within the current research. Firstly due to the small number of participants the generalisability of qualitative research will always be limited. However, where the findings of these studies are presented alongside adequate contextual information they can provide the reader with a broader understanding of some of the issues experienced by a particular population, which may be relevant to individuals in similar contexts. As such, the findings of this study may be most applicable to PWLD who are involved in self-advocacy organisations. In relation to this the participants interviewed in the current research were a mature cohort, with an age range of 30-60 years old. As such it is important to be aware that the experiences, perceptions and in turn salient aspects of close relationships may differ between this age group and that of a younger or older population. This is due to the different experiences they would have encountered within their lifetimes, relating to changes in attitudes, supports and services over time.

Secondly, it is recommended that IPA research is conducted using a homogenous sample so that any findings may be more generalisable to that specific population (Smith *et al.*, 2009). The current sample was regarded to be generally homogenous as participants were recruited from one organisation and everyone lived in small homes within the community. However, variation was present, for example, where people lived and the services they received. There was also a wide age range across the cohort. As such, the sample could be viewed as being too heterogeneous. Yet the researcher found the variation in accounts actually facilitated the identification of the factors that impacted upon participants' lives and the variety of ways this was experienced, such as power imbalances. Conversely, some may view the homogenous sample as presenting a biased account, for example the PFS ethos statements map on to many of the aspects raised in the theme 'struggling for an ordinary life'. However, as long as the research

findings are considered in light of its context and its applicability to other similar research, such bias in the data does not challenge the validity of the research.

Thirdly, although careful measures were taken to clearly describe the process of the research project, the limitations of the researcher-participant relationship and the avenues of support available to the participants (Appendix D), several individuals made comments about meeting up with the researcher in the future or receiving support from her. This clearly demonstrates the difficulties discussed by Nind (2008) regarding the establishment of the researcher role within a population of individuals whose social networks are often limited and predominantly consist of professionals (Pockney, 2006). Although the procedure developed with PFS to manage such situations was found to work well, the experience highlights the importance of researchers being sensitive to potential misunderstanding and misinterpretation that could develop.

Finally, it cannot be guaranteed that all participants had a learning disability as this diagnosis requires a comprehensive assessment to be carried out and specific criteria to be met, as defined by the British Psychological Society (2000). It was not considered that it would be ethically appropriate or advantageous to the study for the researcher to conduct these assessments nor to enquire about such diagnostic procedures, as diagnostic labels and these processes were not central to the research question. Further, it was considered that such actions may change the dynamic between the participants and researcher. It is possible that participants' perception of the researcher could have been influenced by their previous experiences of health professionals and diagnostic labelling, which could impact upon the information provided at interview. As a result the cohort may be less heterogeneous than originally considered. However, it was also felt that the individuals' active membership within a group developed to support people who are defined as having learning difficulties was an adequate indicator that the experiences of the individuals recruited through this organisation would vary from that of the mainstream population. This was considered to be important, as it was this variation in experience that the research question was developed to explore.

8.3 Clinical Implications

This research highlights the need for those who support PWLD to consider if they are meeting the core aspects highlighted within the 'Struggling for an ordinary life' theme. The author suggests that if the foundations of valuing, accepting and supporting independence are met then PWLD would be more likely to obtain the 'normal relationships' they desire. It is proposed that two key aspects need to be attended to in order to establish this foundation. These are: the attitudes of those who support PWLD, and the potential for these individuals to overprotect PWLD. The need to address attitudes was also highlighted by Lafferty (2008). She proposed that to enhance the quality of life of PWLD family and staff members need to become more liberal and accepting of PWLD and their relationships. As such, the author suggests that services should ensure that staff are adequately trained and supervised, and that families receive appropriate support. Further, it is considered important that management drive any changes regarding the support of inter-personal relationships, to ensure that staff feel confident implementing this support (Lafferty, 2008). These measures would ensure that PWLD receive appropriate guidance and assistance regarding relationships, which could reduce opportunities for PWLD to be overprotected as discussed by McConkey & Smyth (2003) and Bane *et al.* (2012). It may also increase their independence enabling them to experience typical relationships, which are often lacking (Richardson & Richie, 1989a). This would allow PWLD to learn from the variety of positive and negative experiences present in relationships. The author also proposes that this is an area that needs to be carefully considered by professionals involved in 'Adult Support and Protection' or 'Safeguarding Adults' procedures (Department of Health, 2011; Scottish Executive, 2007). Professionals need to be aware of the negative impact that overprotecting PWLD can have upon their interpersonal lives, whilst also restricting their ability to learn and develop interpersonal skills. Lastly, it is considered that developing this foundation could also go some way to address the power imbalances described by participants. Increasing independence and a respect for their views would enhance feelings of control and elevate PWLD from the powerless position that many participants described within this and previous research.

Participants within this project also highlighted the importance of feeling safe in relationships, which was commonly lacking. There are a number of factors that may contribute to this lack of safety. As well as this study, Pockney (2006) and Nunkoosing and John (1997) commonly observed participants who described their relationship with support workers as close. As such value is placed on these relationships the high turnover of support staff that support PWLD (Hatton *et al.*, 2001) is concerning. Such instability would contribute significantly to a lack of safety in relationships. Pockney (2006) also discussed the high amount of time this population often spends with support staff who are expected to provide a professional and fair service. This typically involves ‘professional distancing’ from the people they support. Pockney (2006) suggests this often creates cold and aloof relationships, which prevent over engagement. As participants’ descriptions of safe relationships generally contain an unconditional element this professionalism would also limit the extent to which safety could be experienced in these relationships. However, the opportunity for PWLD to form safe relationships with peers is also commonly limited, as services often change or cease due to financial factors. Mencap (2012) recently discussed the inadequate social care supports many PWLD experience and how this can result in individuals not having adequate choice or control about the services they receive. This is reported to be exceptionally common in the current political and economic landscape due to the cuts being made by central and local government. Mencap (2012) particularly highlights cuts in day services and the negative impact that these have upon the social networks of PWLD. Clearly such cuts in services can sever relationships, but even where contact is maintained it is possible that cuts can significantly impact upon the ‘safety’ and ‘useful’ aspects of relationships. Therefore, the author suggests that those who work with PWLD need to be vigilant to any changes in services and the impact that this may have upon the social networks of the people they support. It would be beneficial to assist individuals to maintain relationships in other ways where this is possible, however, this will not always be viable. Thus, it is important that emotional support is provided in relation to the losses that these individuals will experience.

The author would encourage those who support PWLD to facilitate the discussion of emotional difficulties, particularly in relation to interpersonal relationships, as this was observed to be a particular area of difficulty within the study. Being given the

opportunity to discuss experiences and feelings whilst receiving emotional support from an accepting other would not only be emotionally beneficial (Grant *et al.*, 2010), but could also facilitate the development of knowledge regarding emotions and relationships. It may also enhance an individual's expressive ability (Johnson *et al.*, 2003). Further, open discussion and support may go some way to addressing the taboo that surrounds couple relationships in this population. Lastly, increasing PWLD knowledge and ability to share their feelings and experiences could also reduce their vulnerability (Kelly *et al.*, 2009; Thompson, 2001; Yacoub & Hall, 2008) and their likelihood of engaging in inappropriate behaviours due to a lack of awareness (Bunyan *et al.*, 1986).

This research has highlighted the importance of a variety of close relationships to PWLD. As the LD population is not a homogenous group (Gates, 2003) it is important that the support they receive regarding relationships is appropriate for each individual (Lafferty, 2008). This needs to be carefully considered by the services that support this population, as participants reported that blanket rules and restriction did not facilitate or enhance their relationships. This is concerning as these elements are acting to restrict the already limited social networks of this population, which is a major difficulty for PWLD. Thus, services need to consider how their rules and regulations may impact upon the lives of the individuals they support and adjust these accordingly, as the relationships of PWLD need to be prioritised to enhance their social and emotional well-being.

8.4 Possibilities for future research

Whilst the findings of the current research are supported by the existing literature the project has highlighted a number of other areas that could be investigated.

Firstly, qualitative research interviewing PWLD predominantly requires that participant's expressive language abilities are sufficient to enable them to participate in an interview process. As such many members of the population are excluded from sharing their experiences. This area has been highlighted by other researchers (Nunkoosing & John 1997). It was also raised by the PFS Chairs Committee during their review of the current research project, which suggests that it is an area that PWLD would like to see addressed. Thus, future research should seek to develop new strategies to allow these individuals to take part in qualitative research. The use of communication aids such as Talking Mats as described by Nind (2008) may be helpful in this process. Where strategies and adaptations are found to be successful these projects should be widely disseminated to encourage further research that may facilitate the voices of these individuals being heard.

Another area that would be interesting to explore is the experience of close relationships at regular intervals across the lifetime of PWLD, perhaps at times of transition. One would expect the process and type of relationships to change alongside the aspects that are most valued within relationships. This form of data could be used to look at a single individual's inter-personal development or to look for patterns across a learning disabled cohort. Data could also be compared to research detailing the interpersonal development of non-learning disabled individuals, which may highlight the impact of environmental constraints on the relationships of PWLD. Finally this method could permit the detailed exploration of specific relationships, such as how they are maintained and develop. As far as the researcher is aware no qualitative longitudinal research has been conducted in relation to the relationships of PWLD.

The current research did not interview anyone who was subject to explicit restrictions such as those implemented by services and professionals to protect vulnerable adults, driven by the 'Safeguarding Adults' guidance (Department of Health, 2011), 'Adult

Support and Protection Act' (Scottish Executive, 2007) or the criminal justice system. McCorkell (2011) did discuss the impact of compulsory care within the community upon the relationships of several participants in her study, however, this was not the explicit focus of the research. As such it would be interesting to explore this area in depth. To explore if the experiences, perceptions and salient aspects of close relationships for these individuals are comparable to PWLD who are not subject to explicit restrictions.

Finally, the author would encourage future researchers to take steps to involve PWLD in the research process, beyond data collection. It was observed that the majority of the qualitative research conducted with this population did not provide feedback. This project provided and requested feedback which was found to elicit a positive reaction from participants and had a beneficial impact upon the research project, ensuring its accessibility and enhancing its validity. Although research has been conducted that has included PWLD as co-researchers (Bane *et al.*, 2012; Change, 2010; Hollomotz & The Speakup Committee, 2008; Johnson *et al.*, 2002; Walmsley, 2001) these projects continue to be rare and should be promoted. This form of research is important as it not only increases awareness of the perceptions and experiences of the population, but is also considered to promote a more valued social role for PWLD (Walmsey, 2001).

8.5 Summary and conclusions

The current study provides a greater insight into the experiences and perceptions of PWLD regarding close relationships. It has also highlighted a number of areas that are considered to be important in the development and maintenance of these relationships. Participants valued close relationships that were safe and useful, but their ability to develop and maintain these was restricted by the imbalance of power and lack of agency encountered. They desired an ordinary life where they would be valued, accepted, supported to be independent and could experience typical relationships which could include physical and sexual intimacy. However, ordinary lives and ordinary relationships were often described to be hindered or prevented due to the power others held and the influence that societal prejudice and judgments continues to have. The limitations faced regarding close relationships were generally viewed as negative experiences for participants, which were often expressed in an indirect manner during interviews. Yet, despite the difficulties participants experienced regarding these relationships they all described them as being important.

The findings of this research may be of particular interest to those who support PWLD and those who inform the services they receive. The author believes that it is also relevant for those involved in the development of policies and legislation as a direct relationship between overprotection and a negative impact upon inter-personal relationships was highlighted by this research. Whilst protecting PWLD against risk is extremely important, this needs to be balanced against the negative impact that overprotection can have upon the lives of these individuals. Overprotection often prevents PWLD from experiencing the negative aspects of life and relationships, which actually helps individuals to develop and learn (Deeley, 2002). Thus, overprotective services can disable people further and prevent them from reaching their full potential. Obviously the balancing of such aspects against risk is difficult to achieve, but it is important that services attempt to do this and start to look at PWLD as individuals with different abilities and support needs. Services should also reflect this in their practice, rather than utilising blanket rules and restrictions. These practices are based upon the assumption that those without LD know what is best for the population, and the understanding that PWLD are a homogenous group, both of which are contested by the

accounts of participants within this research and the current literature. Most crucially, PWLD need to be consulted about their interpersonal relationships and the support they would like to receive regarding these.

It is hoped that the dissemination of the study's findings will provide professionals and those who support PWLD with a greater insight into the lived experiences of close relationships for PWLD.

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10.0 APPENDICES

Appendix A:

Quality assessment criteria table.

Study:

Quality Assessment Criteria	Notes	Rating Score
Aims and Objectives. <ul style="list-style-type: none">• <i>Are the aims of the research clearly stated?</i>• <i>Do the authors discussed why the research is important and relevant for the time it was conducted?</i>		
Research Context. <ul style="list-style-type: none">• <i>Is the context surrounding research setting and participants explicitly mentioned?</i>• <i>Are adequate descriptions of theses contexts provided?</i>		
Research Design. <ul style="list-style-type: none">• <i>Is the qualitative method used appropriate?</i>• <i>Is the research design selected appropriate to address the aims of the research?</i>• <i>Is the selection of the design method used in the research justified by the author?</i>		
Sample Characteristics. <ul style="list-style-type: none">• <i>Is the participant sample appropriate for the research question?</i>• <i>Is the sample clearly described?</i>• <i>Is the selection/recruitment of the sample clearly described? (inc. eligibility criteria, process of recruitment)</i>		

3= Well addressed, 2= Adequately addressed, 1= Poorly addressed, 0=Not reported/not applicable

Data Collection. <ul style="list-style-type: none"> • <i>Is a clear description of the data collection process provided (e.g. interview style/guide, pilot interview, setting)?</i> • <i>Is the method of data collection and volume of data appropriate for the research questions and design?</i> • <i>Is the form of data clearly described (e.g. tape recordings, field notes etc)?</i> 		
Data Analysis. <ul style="list-style-type: none"> • <i>Is an established qualitative analysis method utilised and referenced?</i> • <i>Is an in-depth description of the analysis process provided?</i> • <i>Is the process of developing categories/themes from the original data clearly described?</i> 		
Findings. <ul style="list-style-type: none"> • <i>Are the findings clearly stated?</i> • <i>Are differences as well as similarities within the data discussed?</i> • <i>Does the research achieve what it set out to do? Have the findings been discussed in relation to the original aims/ research questions?</i> • <i>Is there discussion of findings both for and against research argument?</i> • <i>Are the finding supported/evidenced by the presentation of data (e.g. use of direct quotes, theme matrix)? Is this sufficient?</i> • <i>Are the credibility of the findings discussed (e.g. triangulation, participant validation, more than one analyst)?</i> • <i>Are the strengths and weaknesses of the research discussed and addressed?</i> 		

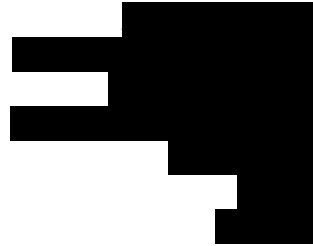
3= Well addressed, 2= Adequately addressed, 1= Poorly addressed, 0=Not reported/not applicable

Reflexivity. <ul style="list-style-type: none"> • <i>Is the researcher self-reflective regarding their values, biased, and inclinations? Do they consider how these might have impacted upon the research process?</i> • <i>Is the relationship between the researcher and participants considered in the research process?</i> • <i>Do the authors consider the impact of the methodology used upon the data obtained?</i> 		
Ethical Issues. <ul style="list-style-type: none"> • <i>Have ethical issues been considered (e.g. recruitment, procedural, relational, exiting ethics)?</i> • <i>If ethics issues are raised did the researcher discuss how they managed these during and after the study?</i> • <i>Has ethical approval been sought and is it explicitly referenced?</i> 		
Contribution to existing Knowledge. <ul style="list-style-type: none"> • <i>Does the research add knowledge, enrich understanding or increase confidence in existing research within the area?</i> • <i>Does the research interconnect the existing literature to the research findings/interpretations?</i> • <i>Are socio-cultural and clinical implications of the research considered?</i> • <i>Are future areas of research identified?</i> 		

3= Well addressed, 2= Adequately addressed, 1= Poorly addressed, 0=Not reported/not applicable

Appendix B:

Recruitment cover letter.



Telephone – [REDACTED] Email – [REDACTED]

4th April 2011

Mr [REDACTED]
[REDACTED]
[REDACTED]

Dear XXX,

Thank you for your help recruiting participants to this research project. Your assistance in issuing invitations to the members of People First is really appreciated.

Please find enclosed a Project Summary Leaflet. The leaflet details what the project is, why it is being done and why members of People First might be interested in taking part. I would be most grateful if you could present this information to your members by talking through the leaflet, and then asking if anyone is interested in taking part. I have provided several copies so members may have a copy if they wish.

I have also enclosed a copy of the project's Participant Information Booklet. The booklet will provide you with more detailed information about the project. Please go through the booklet with anyone who expresses an interest in taking part in the project, to help them decide if they would like to meet with me. I will also go through this document with potential participants as part of the consent process and to ensure that it is appropriate for them to take part.

If individuals come forward please ask if they are happy for me to contact them directly or if they would prefer for any meetings to be arranged through yourself. If they are happy to be contacted directly please ask them to provide their full name, address and telephone number. If anyone is interested in taking part please contact me using the details above, as soon as possible.

If you or your members have any concerns or questions I am very happy to answer these directly. Members are welcome to contact me themselves or via yourself.

It would be wonderful if all invitations could be issued during April, but please let me know if this is not possible. Thank you again for your assistance. I hope to hear from you soon.

Kind Regards,

Faye Sullivan.
Trainee Clinical Psychologist.

Appendix C:

Project summary leaflet.

Due to copyright restrictions some of the images presented within this document are different to those used with participants. All images presented here are copyright free, used with the permission of the copyright holder or are used in accordance with licensing agreements. Image sources:

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What are close relationships like for people with learning difficulties?



PROJECT NAME

What are close relationships like for people with learning difficulties?

WHO IS DOING IT?

My name is Faye Sullivan.



I am training to be a clinical psychologist. I am doing this project as part of my training.

WHAT IS THE PROJECT ABOUT?

Finding out what close relationships are like for people with learning difficulties.

WHY IS THE PROJECT BEING DONE?

There have been very few projects that ask people with learning difficulties about **their** experiences, opinions and feelings about close relationships.

Most projects have spoken to the families of people with learning difficulties, or the people who support them.

More projects need to be done with people with learning difficulties themselves.

It is important to know what people with learning difficulties think and feel about close relationships:

- Because their voices and opinions are not heard as much.
- So the people who support them (like carers, doctors, psychologists, and social workers) can find out what life is really like for people with learning difficulties.

WHY MIGHT YOU BE INTERESTED IN TAKING PART?

- This project will let the people who take part tell others about their opinions and experiences of close relationships.
- Hearing about the opinions and experiences of the people who take part could change what people think.
- People might become more understanding about close relationships for people with learning difficulties.
- Those supporting people with learning difficulties might change the way they work or encourage change in service providers.
- The project could show other researchers and professionals that talking and listening to people with learning difficulties is better than only talking and listening to their family or support workers.

WHAT WOULD YOU HAVE TO DO?

- You will have to meet with me 1 or 2 times.
- I can meet with you at your home or at your local People First base.
- During the meeting I will ask you about your experiences and opinions about close relationships.
- If at any time you decide you don't want to take part, just let me know and the meeting will then end. You will not have to meet with me again.
- Once I have spoken to enough people I will write the project up. **I will not write any names, so no one will know that you took part in the project or what you said.**
- If you agree we will meet one more time so I can tell you what the project found out, and you can tell me what you think about this.
- Taking part in the project will take between 2 and 4 hours of your time in total.

WHAT HAPPENS NOW?

If you would like to take part or want to know more about the project please tell your People First Development Worker. They will let me know that you might be interested in taking part or that you want more information and I will get back to you.

If you do not want to take part you do not need to do anything else.

Project Lead Contact Details

Name Faye Sullivan
Job Title Trainee Clinical Psychologist

Email [REDACTED]

Telephone [REDACTED]

Address [REDACTED]

Appendix D:

Participant information booklet.

Due to copyright restrictions some of the images presented within this document are different to those used with participants. All images presented here are copyright free, used with the permission of the copyright holder or are used in accordance with licensing agreements. Image sources:

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What are close relationships like for people with learning difficulties?



Participant Information Booklet



What's in here?

What is the study about?.....3

Who can take part?.....5

Who can not take part?.....6

Who might find it difficult to take part?7

Who is it for?.....8

What is it for?.....9

What will happen?.....11

Will anyone see what I have said?.....14

When things might happen differently.....17

Do I have to do it?.....18

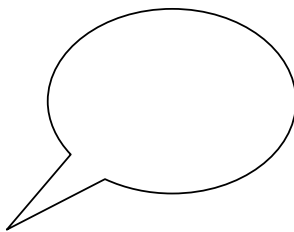
I want to know more – who do I speak to?.....19

If don't agree with this study – what can I do?.....20

What is the study about?



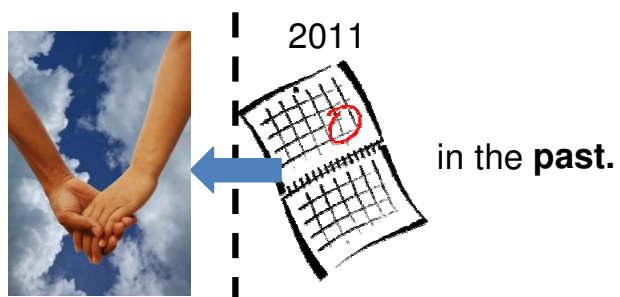
I want to know what close relationships are like for people who have learning difficulties.



I would like to talk to you about any **close relationships** you have



and





I also want to know about what you **think** about close relationships.



Who can take part?



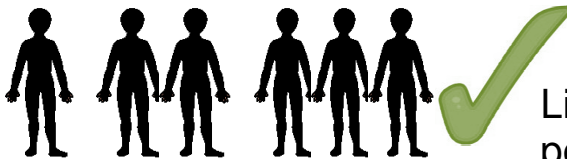
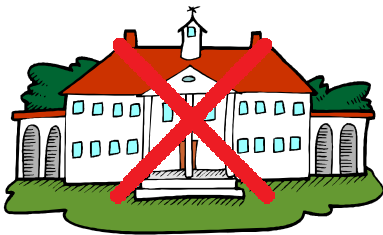
People who are members of **People First**



Speak **English**



Live in the **community**



Live **alone** or with **1** or **2** other people



Who can not take part?



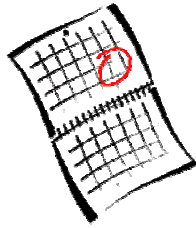
People who have been involved with the **police** about close relationships



People currently involved in **Adult Support and Protection** procedures

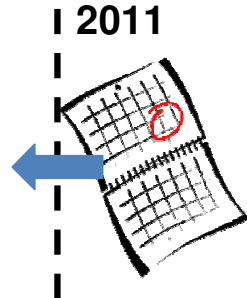
Who might find it difficult to take part?

2011



People who have difficult close relationships **now**

or



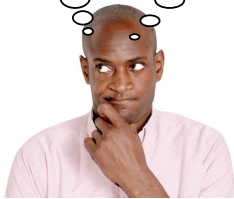
2011

in the **past**

or



had a close relationship with someone who **died recently**



but it is **your decision**.

Who is it for?



My name is **Faye Sullivan**.



I am a student at the University of Edinburgh.



I am training to be a Clinical Psychologist.

What is it for?

?



I am trying to find out what close relationships are like for people who have learning difficulties.



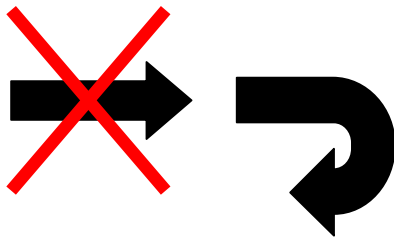
I am doing this to:



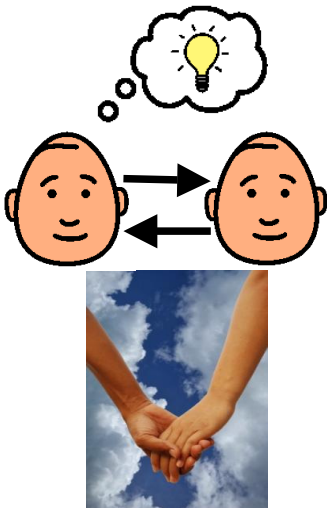
Let people with learning difficulties tell other people what close relationships are like for them.



People who work with people who have learning difficulties will hear about what was said.

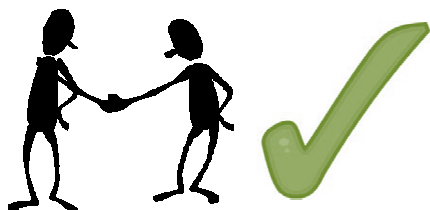


This might **change** how they work and how they support people with a learning disability.



This might help other people be more understanding about close relationships for people with learning difficulties.

What will happen?



If you agree to take part:



I would like to meet with you **2** or **3** different times.



I would like to meet you where you live or at the People First base



I will ask you some questions about close relationships.



I would like to record what you say on tape.



This is so that I don't forget, or mix up anything you have said.



This talk will last for no more than **1 hour**.



If we don't have enough time and you have more to tell me we can meet again.



What you say will typed up on a computer by the secretary.



I will then:



Read what you have said

and



write a report about what people said.

Once the study is finished:



I would like to meet you again to tell you about what I have found out

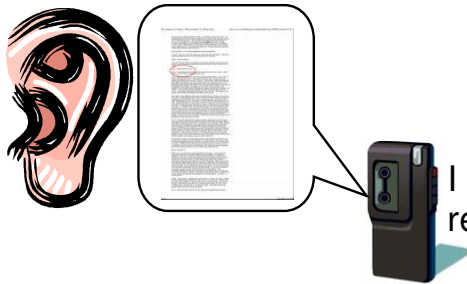
and



to hear what you think about the report.



I would like to record what you said

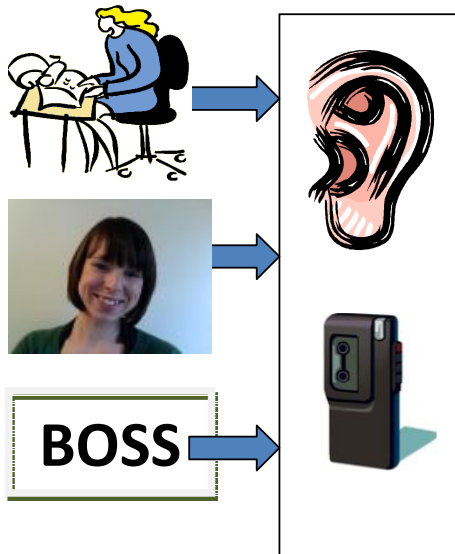


I will listen to what you said about the report

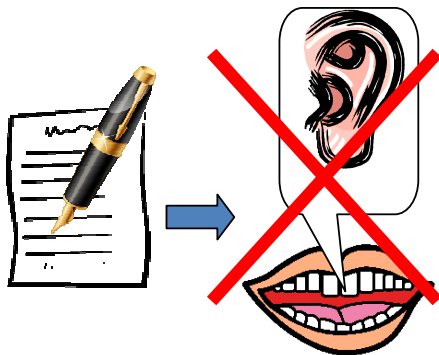


And write about this in the final report

Will anyone find out what I've said?



Only Faye Sullivan, her boss (Dr Keith Bowden) and a secretary will be allowed to listen to your tape.



They have all signed a contract to say they **will not** talk to anyone else about what they hear



What you say will be typed up on a computer by the secretary.

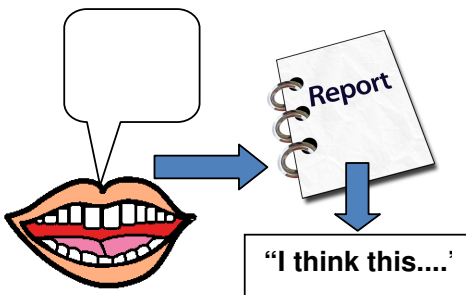


After this is done this I will destroy your recording



Your name will not be used when the recording is typed out.

Mr. [REDACTED] said



Some of the words you have said will be written in the report.



But:

~~Mrs Brown~~

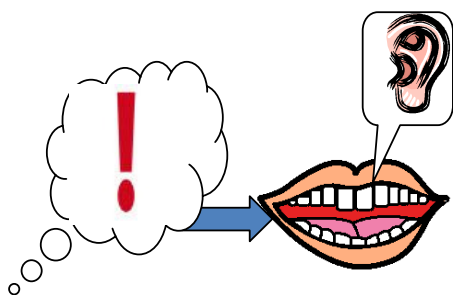
Your name or any other names you say **will not** be used in the report.



This means that no one will know it was you who said it.

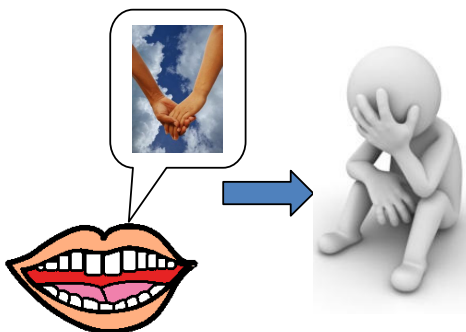


When things might happen differently?



If I thought you, or someone else were unsafe or could be hurt I would tell someone what you said.

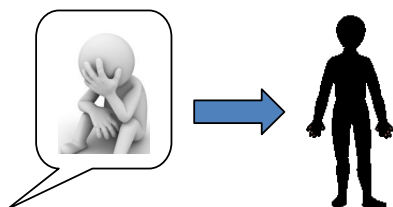
or



If talking about close relationships makes you feel very upset:



I will stop the meeting



I will tell a named member of staff that you are upset.



You can talk to the named member of staff if you would like to.

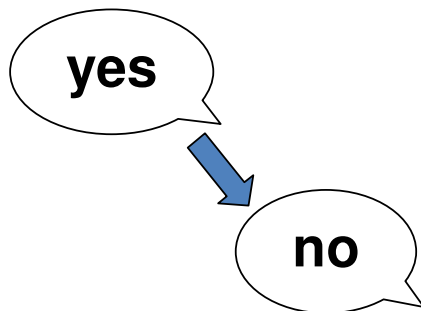
Do I have to do it?



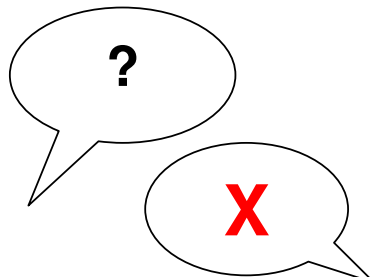
It is up to you if you take part or not.



If you say 'no', this is ok.



You can change your mind any time.



You can say 'no' to any questions you don't want to answer.

I want to know more – who do I speak to?



I will phone you in 1 week to ask if you want to take part.



If you want to talk to me before then you can phone me on:
(01324) 614349



Or send me an email:
faye.sullivan@nhs.net



If you want to know more about taking part in research, you can have a look at:

<http://www.involvingpeople.org.uk/>

If don't agree with this study – what can I do?



If you don't agree with any parts of this study and want to **complain** you can do this through The University of Edinburgh.

Phone the psychology department on:
(0131 651 3972)

Appendix E:

Consent form.

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What are close relationships like for people with learning difficulties?



Consent form





I have looked over the Participant Information Booklet

☐

I have had a chance to talk to someone about the study

☐

I understand it involves meeting with Faye Sullivan 2 or 3 times

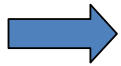
☐

I am happy for Faye to come to my house or People First base.

☐

I agree to our talk being recorded

☐



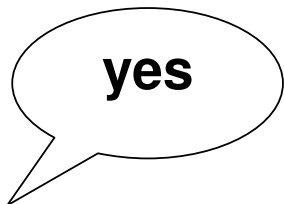
I know that if I say something about me being unsafe or hurt this might need to be passed on to someone else

☐

I know that if I say something about other people being unsafe or hurt this might need to be passed on to someone else

☐

I know I can stop taking part at any time

☐

I agree to take part in this study:

Signed: _____ Date: _____

Researcher: _____ Date: _____

Appendix F:

Interview schedule.

Understanding and experience of close relationships:

1. What do you think *close* relationships are?

Possible Prompts:

- Do you have any close relationships now?...Can you give me an example?
- Have you had close relationships in the past?...Can you give me an example?
- Who are the most important people in your life?
- Who are you close to?

Understanding of different forms of close relationships:

2. Do you think there are different types/strengths/levels of close relationships?

Possible Prompts:

- What are they?
- What's the difference between these?
- Can you tell me about different types of relationships you/other people have?

Identification of important attributes of close relationships:

3. What are the most important things in a friendship/intimate relationship (use their words)...for example your relationship with X?

Possible Prompts:

- What make you think of X as a close friend/ boyfriend/girlfriend?
- What sort of things do you do with X?

4. What are important things you/other people look for in someone they have a close relationship with?

Possible Prompts:

- What are important things you/other people look for in a boyfriend/girlfriend/good friend? (If previously labelled by participant).
- What did you look for in X?
- What did you like/not like about X/Y?

Deciding to enter into close relationships:

5. *How do you decide who to/not to have a close relationship with?*

Possible Prompts:

- How did you decide to become close friends/ boyfriend/girlfriend with X?
- How did you decide to end your relationship with X?

Entering into a close relationship:

6. *What do you have to do to start/develop/make a close relationship?*

Possible Prompts:

- How did you become close friends/ boyfriend/girlfriend with X?
- What happened so you could be X's friend/ boyfriend/girlfriend?
- What did X/you do to start being friends/ boyfriend/girlfriend /in a relationship?
- How do you know when you're in a relationship?

The meaning of close relationships:

7. *What does it/would it mean to you to have a close relationship (...or type of relationships named by the participant)?*

Possible Prompts:

- What does it/would it be like.....
- What does it/would it feel like.....
- Is it important for you to have/be in close relationships?....why?
- What does it mean when you say someone is a close friend/ boyfriend/girlfriend?

General open question to end:

8. *I've been asking you a lot of questions – is there anything else about relationships you would like to tell me?*

Appendix G:

Confidentiality agreement.

Confidentiality Agreement

THIS AGREEMENT is made on 15.04.2011

BETWEEN:-

- (1) **XXXXXX** on behalf of **XXXXXXXXX** whose registered office is at **XXXXXXXXX** ("**Service Provider**"); and
- (2) **FAYE SULLIVAN** of the University of Edinburgh (the "**Client**").

WHEREAS

- (A) The Client is a Doctoral student at the University of Edinburgh undertaking a Doctorate in Clinical Psychology.
- (B) As part of the requirements of the Doctorate course the Client is required to undertake a piece of research. As part of the data collection for this research the Client has carried out interviews that have been digitally recorded.
- (C) The Client has appointed the Service Provider to carry out transcription services of these interviews (the "Contract").

IT IS HEREBY AGREED as follows:-

- 1. This Agreement is being entered into by the parties to ensure (without limitation) the confidentiality of:
 - (a) the interviews;
 - (b) the transcriptions of the interviews carried out by the Client;
 - (c) any information relating to participants including any content that is disclosed during the interview or any information that the Service Provider has been told is confidential; and
 - (c) any further confidential information obtained by the Client that becomes known to the Service Provider in relation to the interviewees (together the "Confidential Information").
- 2. The Service Provider agrees that they shall not during the course of the Contract and at all times (without limitation) after the termination the Contract (howsoever such Contract is determined), directly or indirectly, make use of, or disclose (to a third person, company, firm, business entity or other organisation whatsoever) or exploit for their own purposes or for those of any other person, company, firm, business entity or other organisation whatsoever, any Confidential Information relating to the interviews or belonging to the Client.
- 3. In complying with this Agreement the Service Provider must refrain from discussing, reading or disclosing any Confidential Information openly in public areas, such as (without imitation), on trains, buses and airplanes, on mobile telephones, or in restaurants. If the Service Provider is in any doubt as to the extent and/or the ambit of these obligations the Service Provider shall discuss such query or concern with the Client.
- 4. The Service Provider acknowledges that the Client reserves the right to terminate the Contract immediately should the Client become aware of any breach of this Agreement.

5. The failure of the Client to enforce or to exercise, at any time or for any period of time, any term of or any right arising pursuant to this Agreement does not constitute and shall not be construed as a waiver of such term or right and shall in no way affect the Client's right later to enforce or exercise it.
6. This Agreement shall be governed by and construed in all respects according to the laws of England and Wales and the parties hereby submit to the exclusive jurisdiction of the English courts in all matters relating to this Agreement.

IN WITNESS WHEREOF this Agreement has been executed by the parties on the date which first appears in this Agreement.

Signed by
PRINT NAME SIGNATURE

duly authorised for and on behalf of [XXXXXXXXXXXXXX]

Witnessed by
PRINT NAME SIGNATURE

.....
ADDRESS

Signed by
(Researcher) PRINT NAME SIGNATURE

Appendix H:

**Example coded transcript:
Illustrated using interview with John.**

Stage 2 and 3 of the analysis process are illustrated below, using a short extract from John's interview.

The three levels of exploratory coding are illustrated using different text styles:

- Descriptive coding - describes content and notes interesting or significant things. Illustrated by normal text.
- Linguistic coding - focused on exploring the specific use of language use. *Illustrated by italics.*
- Conceptual level - interpretative and interrogative exploration of the text. **Illustrated in bold.**

Comments in **red** are reflections on the potential influence of the researcher upon the interview narrative.

Emergent themes are demonstrated in the right hand column, which is demonstrative of the third stage of the analytic process.

Original Transcript	Initial Notes (stage 2)	Emergent themes (stage 3)
<p>Int Okay</p> <p>John And I see her in York sometimes on a Wednesday night Action for People's in Cottingham, Yorkshire [inaudible] Um, her [inaudible]'s a teacher</p> <p>Int She what sorry?</p> <p>John [inaudible] a teacher</p> <p>Int Okay</p> <p>John And I meet with her on a Thursday morning, a Thursday she works at a restaurant at the Lion on the Green Road. Um, Saturday and Sundays I go and visit her. I take the bus out and go and visit her.</p> <p>Int Aha</p> <p>John Bus [inaudible]. The 165 is a bigger bus</p> <p>Int So what sort of things do you get up together?</p> <p>John Oh we'll have a coffee, or sometimes we'll have breakfast</p> <p>Int Aha</p>	<p><i>Not regular?</i></p> <p>Contact at local group (supported, people with LD)</p> <p><i>Repeat I – independent or one way effort?</i> Girlfriend works – Able</p> <p>Regular contact out with services/supports – several times a week</p> <p>Travels on bus to visit girlfriend – Able/independent</p> <p>Description of transport – exhibition of knowledge/ability</p> <p>Activities as a couple</p>	<p>Regular contact</p> <p>Other as capable</p> <p>Capable</p> <p>Knowledgeable</p>

John	Um, she makes me a coffee, I make her a coffee, we have a coffee, we'll listen to a CD in the bedroom or we'll go for a lovely walk. We'll have lunch together	<p><i>Shift from I to we – unity</i> couple identity Make each other drinks reciprocity/equality/care Bedroom specified not elsewhere - bedroom as place spend time together – always accepted/allowed? Adult time? listen to music – very acceptable behaviour – defending against potential sexual interpretation?</p> <p>Many activities as couple – variable choice/independence <i>Language re: activities idealised</i></p>	<p>Activities as a couple</p> <p>Reciprocity</p>
Int	Yeah		
John	Sometimes we'll go to the pictures, cinema, or sometimes we don't. We'll go do something, somewhere nice.		
Int	It sounds like you do lots of all sorts of different things		Idealised
John	Sometimes we'll take a bus and go away for the day. Go into York and do something nice. Go for a cup of coffee and for something to eat and all that	<p>Day trips on the bus <i>Only do nice things - idealised</i> Whole day on own (taking bus) able/ free unrestricted Many activities – choice, unrestricted, able, normal? <i>All lovely/nice – Romantic/idealised – is it just nice being with her/in a couple relationship?</i> Interviewer expressed own positive perception of activities/relationship. <i>'Whatever' implies that other things are possible</i> – just to being with each other important not activity, or free to do many things</p>	Independent as couple
Int	Brilliant		
John	Or do a bit of shopping or whatever.		
Int	Lots of different things		
John	Monday I took the train at the train station, last Monday I took a train up to Malam.	<p>Independent travel - long distance <i>Repeat I - alone</i> independent</p>	Importance of contact not activity
Int	Aha		
John	Not far from Skipton, um. Just spent the day in Malam with my girlfriend. Bought a strawberry ice-cream at the harbour beside the boats just a wee ice-cream shop. And it's next to a wee white house where you actually book it to stay for a week's holiday and that, Um. And we went for coffee in the evening, a wee coffee shop call the Flower house, with a flowers lying beside it	<p><i>Emphasis on his experience – not joint</i> Spent day with girlfriend alone independent adult /normal relationship</p> <p>High detail re: trip – exhibiting knowledge <i>Language had idyllic quality</i></p>	<p>Independent as couple</p> <p>Knowledgeable</p> <p>Idealised</p>

Appendix I:

**Example of emergent themes list:
Generated from analysis John's interview.**

Emerging theme	Page Number	Line Number
Abandonment by family	46	1306 – 1311
Absence of experience versus absence of knowledge	30	843 – 859
Acceptance by others family	35	1005 – 1013
Acknowledging limitations [2]	42	1189 – 1190
	42	1211 – 1212
	6 – 7	148 – 179
Activities as a couple [3]	21	591 – 605
	22	620 – 625
Adult relationship as taboo	42 – 43	1214 – 1220
Being desired as important	23 – 24	661 – 677
Capable [2]	5	138 – 139
	41	1157 – 1177
Care as important	1	17
Care as important in relationship	48	1365 – 1372
Care for others family	35	997 – 998
Caring role in relationship [2]	10 – 11	289 – 299
	17	482 – 490
Clarification	45	1275
Close relationship as stable and caring	46	1314 – 1350
Close relationships as singular [2]	29	821 – 833
	30 – 31	858 – 872
Close relationships as strong feelings	1	5 – 22
Close relationships as strong feelings	31	882 – 890
Commonality as important	4	93 – 97
Commonality desired	19 – 20	549 – 551
Commonality initiating relationship	15	406
Communication regarding problems as important	13	361 – 363
Contact with others family as important	34	974 – 984
Contacts as important	29	814 – 815
Desire for idealised relationship	19	531 – 544
	38 – 39	1076 – 1123
	40	1140 – 1156
Desire for stereotypical life [4]	42	1194 – 1203
	43	1225
Desire to be normal	20	560 – 568
Emotions defended against	26	730 – 730
Equality	40	1140
Family as home	33	934 – 950
Family as important	44	1258 – 1261
Family as uncaring	46	1302
Feelings as eternal	21	580
Feelings for partner as eternal	23	661 – 662
For better for worse (caring role/stability)	36	1037 – 1039
Happiness as fundamental in marriage	2	56 – 57
Happiness as important [2]	4	93 – 97
	28	795 – 799
Happiness as results of other	31	885 – 890

Helping role as important	46	1312 – 1329
Honesty [3]	35	988
	48	1354
	49	1397
Honesty regarding feelings	21	580 – 582
Idealised [11]	6	158 – 173
	8	206 – 222
	10 – 11	289 – 309
	14	384 – 400
	15	424 – 425
	17	468 – 478
	21	591
	22	620
	23	652 – 653
	19	525 – 526
Importance of choice	15	406
Important of contact not activity	7	179
Increased freedom desired	42	1194 – 1203
Independent as a couple [2]	6–7	158 – 179
	7–8	183 – 210
Involvement of others in life	42	1214
Involvement of others in relationship [2]	42 – 43	1214 – 1220
	44	1244
Knowledge of family [2]	44	1265 – 1268
	45	1279 – 1285
Knowledge of other [6]	8– 10	217 – 274
	11 – 12	317 – 329
	14	376 – 380
	19	549
	34	956 – 970
	23	637 – 647
Knowledgeable [7]	4	110 – 116
	5	136 – 144
	7	183 – 200
	14	384 – 400
	15 – 16	433 – 457
	22	609 – 615
	41	1168 – 1171
Lack of agency	43	1238 – 1239
Lack of emotion regarding family	45	1290 – 1295
Limited emotional expression	49	1410 – 1411
Long-term relationship as important	25	695 – 720
Love as fundamental in marriage [2]	2–3	50 – 68
	13	347 – 358
Love as happiness [2]	11	305 – 306
	12 – 13	344 – 361
Love as important	1	5–13
Love as unconditional	11	305

	2	41
Marriage as eternal commitment [3]	3	69 – 70
	13	358 – 360
Marriage as ultimate close relationship [2]	2	33 – 40
	3	78 – 85
Other as capable [2]	5	135 – 136
	22	633
Others needs before own [2]	10	285
	11	305 – 310
Physical appearance as important	18	492 – 509
Physical attraction initiating relationship [2]	17	469 – 471
	18	509 – 515
Physical intimacy defended against	24	681 – 691
Positive regard as eternal	17	476 – 478
Power imbalance	43	1215 – 1217
	25	701 – 720
	26	746
	27	780 – 781
	32	920 – 921
Feeling verses literal knowledge [6]	32 – 33	923 – 930
	39 – 40	1125 – 1030
Provider role	38	1076 – 1078
Providing for other [2]	15	424 – 426
	17	490
Reciprocal care as important [2]	37	1054 – 1055
	39	1099 – 1123
	4	96 – 97
Reciprocal communication regarding problems as important [3]	36	1026 – 1033
	37	1049 – 1053
Reciprocal feelings	27	754 – 758
Reciprocal happiness as important [2]	29	814 – 815
	32	901 – 902
Reciprocated feelings	21	583
Reciprocated feelings as important	23	655 – 662
Reciprocity	6	154 – 155
Reciprocity as important	28	800
Regular contact	5	120 – 139
Rejected versus accepted	25 – 26	714 – 737
Relationship as caring for other	32	908 – 912
Relationship as developing traditionally	32	910 – 921
Relationship as eternal commitment	32	908 – 911
Relationship as happiness [2]	47	1339 – 1340
	48	1373 – 1374
Relationship as limited	28	800 – 805
	13	370 – 371
Relationship as long-term [3]	26	731 – 745
	27	760 – 781
Relationship as stable	24	690 – 691

Relationship as stable and reliable	48	1382 – 1386
Relationship as unique	48	1373
Relationship difficulties defended against	36	1026 – 1030
Relationship official	26	750
Reliability as important	1	5–10
Romanticised view	1	21
Rules and regulations impacting on relationship	44	1249 – 1250
Sexuality defended against	24	684 – 686
Sharing experiences as positive	49 – 50	1414 – 1418
Stereotypical behaviour	20	577
Uncertainty	33	936 – 946
Uncertainty acknowledged	34	971
Unconditional positive regard for other [3]	10	279 – 281
	11 – 12	316 – 333
	31	882 – 884
Unconditional positive regard for others family	35	992 – 993

Appendix J:

**Table of super-ordinate and emergent themes:
Identified from analysis of John's interview.**

Super-ordinate themes	Emergent themes [] indicates frequency of theme
Balanced appraisal of self	Acknowledging limitations [2] Capable [2] Honesty [3] Honesty regarding feelings Increased freedom desired Knowledgeable [7] Uncertainty Uncertainty acknowledged
Close relationships as positive strong feelings	Close relationships as strong feelings Happiness as fundamental in marriage Happiness as important [2] Happiness as results of other Love as fundamental in marriage [2] Love as happiness [2] Love as important Relationship as happiness [2] Unconditional positive regard for other [3] Unconditional positive regard for others family <i>Lack of emotion</i> Lack of emotion regarding family Limited emotional expression <i>Negative emotion</i> Relationship difficulties defended against
Involvement of others in relationship	Acceptance by others family Adult relationship as taboo Sexuality defended against Contact with others family as important Involvement of others in life Involvement of others in relationship [2] Lack of agency Physical intimacy defended against Power imbalance Rules and regulations impacting on relationship
Normal as Ideal	<i>Desire for a stereotypical life</i> Activities as a couple [3] Desire for stereotypical life [4] Desire to be normal Independent as a couple [2] Relationship as developing traditionally Relationship keepsake

	<p>Stereotypical behaviour</p> <p><i>Idealised</i></p> <p>Idealised [10]</p> <p>Romanticised view</p> <p><i>Knowledge of other</i></p> <p>Knowledge of other [6]</p> <p><i>Reciprocity as important</i></p> <p>Equality</p> <p>Reciprocal care as important [2]</p> <p>Reciprocal feelings</p> <p>Reciprocal happiness as important [2]</p> <p>Reciprocated feelings</p> <p>Reciprocated feelings as important</p> <p>Reciprocity</p> <p>Reciprocity as important</p> <p><i>Physical attraction</i></p> <p>Physical appearance as important</p> <p>Physical attraction initiating relationship</p> <p>Physical attraction initiating relationship</p>
Relationship as caring for other	<p>Care as important</p> <p>Care as important in relationship</p> <p>Care for others family</p> <p>Caring role in relationship [2]</p> <p>Family as uncaring</p> <p>Helping role as important</p> <p>Others needs before own [2]</p> <p>Provider role</p> <p>Providing for other [2]</p> <p>Relationship as caring for other</p>
Relationship as stable and reliable	<p>Close relationship as stable and caring</p> <p>Feelings as eternal</p> <p>Feelings for partner as eternal</p> <p>Long-term relationship as important</p> <p>Love as unconditional</p> <p>Marriage as eternal commitment [3]</p> <p>Positive regard as eternal</p> <p>Feeling versus literal knowledge [6]</p> <p>Relationship as eternal commitment</p> <p>Relationship as long-term [3]</p> <p>Relationship as stable</p> <p>Relationship as stable and reliable</p> <p>Reliability as important</p> <p><i>For better for worse</i></p> <p><i>Importance of Contact</i></p>

	<p>Contacts as important Important of contact not activity Regular contact <i>Unreliability</i> Abandonment by family</p>
Removed	<p>Close relationships as singular Family as home Family as important Importance of choice Knowledge of family [2] Other as capable [2] Rejected versus accepted Relationship as limited (?) Relationship as unique Absence of experience versus absence of knowledge Emotions defended against Clarification Close relationships as singular <i>Commonality</i> Commonality as important Commonality desired Commonality initiating relationship</p>

Appendix K:

**Table illustrating super-ordinate and sub-themes
representing whole participant group.**

Super-ordinate theme	Sub-themes
Relationships feeling safe and being useful	Relationships feeling Safe
	Relationships being useful
Who's in charge?	One person in charge in a relationship
	Other people in charge of my relationships
	Other people in charge of my life
Struggling for an ordinary life	Being valued by other people
	Being able to do things on my own
	Being accepted
	Being able to have a normal relationship
Touching people in relationships	Is wrong
	Unsafe to talk about
	Suggesting is safe
	No freedom or fun
	Being touched
Hidden feelings	Feelings being covered up
	Feelings being played down

Appendix L:

Reflective commentary.

Overview

The hermeneutic phenomenological position is a strong influence within Interpretive Phenomenological Analysis (IPA), as such it is understood that analysis will always involve some level of interpretation (Smith *et al.*, 2009). The investigation of how participants make sense of their experiences and how they derive their meaning requires the researcher to engage in interpretive activity. Within this area it is assumed that research findings are the product of the researcher and the researched (Larkin *et al.*, 2006). As such the researcher must adopt a reflexive practice during the research process. It is considered that this not only increases self-awareness of the researcher's feelings and values but also increases the transparency and rigor of the research. This is achieved by the reader being provided with an account of events and influences during the research process. They are also made aware of how the researcher's past experiences, beliefs and theoretical stance could have impacted upon the findings of the research.

This commentary describes the contribution of the reflective diary and details the reflections made at each stage of the research process. It also contains a section which provides an overview of the researcher's personal context describing both their influences and background. As this is a commentary of the researcher's reflections it has been written in the first person.

Reflections on my own context and perspectives

I am a 29 year old female living in the South East of Scotland, but I was born and brought up in the North of England. I have been in a long-term couple relationship throughout the research process, and I consider myself to have a wide variety of other close relationships in my life, which I value greatly. I have recently completed elective placements in family therapy and psychosexual couple therapy. As such my current thinking and practice is strongly influenced by systemic practice and theoretical understanding. However, my clinical practice is also influenced by the perspective of psychodynamic and narrative therapy, as well as community psychology.

Clinically I have worked within a learning disability service as a Trainee Clinical Psychologist for over four years. Prior to this I worked as an Assistant Psychologist within a learning disability team in the North East of England. I have worked in both inpatient and community settings. Within the learning disability service that I currently work the majority of my therapeutic work is conducted on a one to one basis, although I have also worked with couples, families and those who support people with learning disabilities.

With this research project I hoped to add to the limited literature surrounding the close relationships of people with learning disabilities (PWLD) from their perspective. The choice of IPA not only suited the research area but it's foundations in the philosophy of qualitative epistemology was also compatible with my own position and beliefs. Specifically that an individual's knowledge and experience of the world is not an objective appraisal of reality but shaped by their subjective perception and cultural influences (Yardley, 2000). Further, I felt that the broad focus of the question would

enable participants to focus on relationships and experiences that felt important to them, which coupled with the ideographic nature of analysis would enable the findings of the research to remain firmly rooted in their accounts and thus what was important to the participants.

Reflections on the research process

Recruitment

The involvement and support of People First Scotland throughout the recruitment process was invaluable. It provided a means for participants being able to hear about the research and investigate potential participation thoroughly before any contact was made with the researcher. I felt that participants being able to self-elect to take part without the pressure of influential others was important, particularly within this population.

There were times where misinterpretation resulted in the process not going as planned. For example the draft documents sent for consideration by the Chair's Committee were accidentally sent out to Development Workers and had to be recalled. Although anxiety provoking at the time, this glitch did not appear to have any detrimental effect when the recruitment process actually commenced. Throughout the process of recruitment I was informed by several Development Workers about a number of members who self elected but did not meet the eligibility criteria. For example several people lived in large group accommodation and one member was fighting for custody of their child. It felt incredibly difficult to say that these individuals could not participate in the project. It felt that by saying this I was silencing their voice. It was at this time that I became more aware of my own wish to advocate for this group of people, and how this sat in contrast to the strict boundaries that the researcher role requires. This led to a discussion with my supervisor about potentially changing the eligibility criteria. In this meeting we reflected upon the restrictions that research is bound by (particularly for a clinical doctoral thesis), and the frustration that this can provoke. Reflecting on this process highlighted the limits of the project and my role, and as such the eligibility criteria did not change.

Interview process (individual & general)

In the early stages of the interview process I felt anxious as I had little experience of qualitative research and I had never used IPA. For example, I was very aware that I needed to avoid any leading or suggestive questions that could bias participants' accounts and although I had an interview schedule to guide the interview process I felt a huge sense of responsibility to gather enough information. On reflection I suspect that this was related to the work of other authors who had suggested that the data PWLD would generate would not be rich enough to conduct IPA. At this time I also wrote about the difficulty of questioning and prompting participants and I did not want to be intrusive but conversely I did not want to appear disinterested.

Several of the participants experienced speech difficulties, which alongside a strong Scottish accent made the interview process quite difficult at times. On the whole the interview process went well and I felt that participants were able to share their stories with me. However, there were moments that I felt disabled as I could not understand

what the person was saying and could not interact with them as I would have liked to. I also felt guilty when asking someone to repeat themselves, and frustrated when I missed something that was obviously significant. Encountering this difficulty within the interview process highlighted the role of power in the lives of these individuals, and how I was automatically placed in a dominant position being 'able', and they in subordinate roles, in which they had to try and convey their message in a way that I would understand. Emotionally however, it often felt like the roles were the other way around for me, and that I was in a subordinate position as their experiences and voice were the focus of the interaction and my inability to comprehend this at times was frustrating and made me feel powerless. It is possible that these participants could have nominated a third party to assist them in conveying their story but this would have changed the whole dynamic and would again have reinforced the participants' powerless position, through their dependence of others to communicate (Pockney, 2006). On reflection, perhaps using Talking Mats to assist communication would have been empowering at these times, as it could have facilitated communication between the participant and myself without being reliant upon another individual. However I suspect that as the majority of these interviews were successfully conducted verbally, the introduction of this aid would have hindered the flow of the interview.

All participants described the interview process as a positive experience. Prior to interviewing I had not considered the benefit that people may experience from being interviewed. This became more and more apparent as several participants clearly described the limited opportunities that they had to reflect on and discuss this area. This cathartic element of the interview process alongside several participants asking if they could meet with me again to talk about the area, clearly highlighted that the interview served a positive and perhaps therapeutic process for some participants. Initially I was very concerned by this as I had tried to be very clear about the process and the limitations of my role, I felt disappointed that the measures I had taken had not prevented the difficulties that Nind (2008) described regarding the research role and conducting research in an emotive area with a population whose social networks are limited. I was also concerned that this would have a negative impact upon the participants. However, reiterating the limitations of my role and using the procedure arranged with PFS (that participants could receive support and guidance from their Development Worker) was accepted by all of these individuals.

On considering this time in the research process again, I now wonder if some of my concerns are related to the tendency that those who support people with learning disabilities have to over protect. Was I trying to prevent a natural connection or attachment forming so that the participants could not experience negative emotions when a contact ends? Also would there be any way of meeting with and interviewing participants that ensures no attachment or connection is made? If there were, would participants feel comfortable sharing their experiences, and what sort of experience would this be for them? I am confident that the process that took place was ethically sound, participants consented and were fully supported, but it has clearly highlighted my own inner struggle, as a researcher/Trainee Clinical Psychologist who needs to retain a professional distance from participants/clients as opposed to Faye Sullivan the human who wants to and enjoys connecting with people. It has also raised the question of who 'professional distancing' protects, as the research has shown that it not only limits the depth of relationships that PWLD can develop but can also feed into the

overprotection that further disables the population. This makes me wonder if it is actually more protective for professionals and researchers who by maintaining a 'professional distance' do not have to fully acknowledge the emotional impact that they might be having due to the limited and sometimes sporadic contact they have with the people they work with.

Reflections on analysis

As I commenced analysis I felt reassured and comforted by the clear process set out by Smith *et al.* (2009), however, this was quickly replaced by a lack of confidence in my own ability to interpret and follow the process correctly. Supervision and support from peers who had also conducted IPA research reassured me that the anxiety I felt was a typical part of the process, and that what I was doing was appropriate. However, the anxiety I experienced at this time resulted in the analysis of my first few transcripts taking a very long period of time. The process of making initial notes was found to be relatively easy, but when it came to reducing these notes into emergent themes it became apparent that my anxiety had resulted in an excess of detail being retained within the notes, which made their reduction into succinct statements incredibly difficult. Although this improved in the analysis of subsequent interviews it is only now, at the end of the process that I can see how much detail there is and how this could be reduced. At the time I did not have the confidence to exclude these things as I did not feel confident in the process and I was concerned that such exclusions could distort the voice of the participants. In these early stages my role within analysis, through the interpretation of the data felt very scary, and I felt an overwhelming sense of needing to get it right. As I went on I slowly became more accepting that analysis needed to be good enough (Smith *et al.*, 2009) rather than perfect. A helpful process I undertook at this time was triangulation, from which my supervisor and I could discuss analysed transcripts and the themes that had emerged from these. Discussing these themes and knowing that they were plausible to another researcher (who was a very experienced clinician working in the learning disabilities area) was reassuring and developed my confidence and ability to interpret the data. Nearing the end of the analysis process I attended an IPA analysis workshop run by Paul Flowers, which I found hugely reassuring and provided me with a massive sense of relief that the analysis process I had conducted was good enough.

At the end of the analysis process I described the super-ordinate themes I had identified from the data to my supervisors. 'Touching people in relationships' was not as prevalent as the others but felt incredibly powerful and I was uncertain if it was appropriate for this to be an overarching super-ordinate theme. The responses of my supervisors highlighted the passion with which I discussed this theme and the power that it conveyed. Again supervision was invaluable in supporting and developing my confidence, which enabled me to value my interpretation of the data, and it was this process that led to its inclusion within the final five themes.

Writing

The writing of the results section followed a very similar pattern to that of analysis, initially containing far too much detail, particularly surrounding the interpretations that I had made. It felt difficult to remove this justification from the final results section as it

meant that my interpretations were exposed and open to be judged. Yet again discussion with my supervisors at this time encouraged me to have confidence in my interpretations and present them clearly. The process of editing the results section also involved the removal of some extracts. One of my supervisors suggested several extracts that could be removed as they did not find them as illustrative of themes as others. I found my reaction to their suggestions interesting, some I agreed with, but others evoked a strong emotional response as I viewed them to be incredibly powerful extracts. I reflected on this for some time, and tried to decipher if my reaction was a desire to protect my own interpretation, if my explanations of the extracts had been inadequate or was it that the power and significance of these quotes had been conveyed during the interview through transference which could not be observed to the same extent within an extract alone? Based on the powerful reaction I experienced, the significance the quotes conveyed at interview and discussions with another supervisor I decided to keep these extracts within the results section. However, this clearly highlights the co-construction of meaning and my role in the interpretation of the data.

Respondent validation

In my initial proposal it was described that I would feed back the findings of the research and obtain respondent's opinions about these. This was felt to be an important process given the historical context of research being 'done on' rather than involving PWLD (Kiernan, 1999) and the current focus on the involvement of PWLD in research. It also importantly serves as an appropriate means of obtaining a measure of quality. As the research process went on I became increasingly aware of the co-construction of the findings (Salmon, 2003) and the debate within IPA as to whether respondent validation is appropriate. I was concerned that participants would find my analysis of their accounts to be removed from their original meaning and that they may feel that I had misunderstood and presented their experiences wrongly. However, I was aware that the possibility of receiving feedback had been discussed with all of the participants and that all had requested that I contact them when the findings were complete. On contacting participants seven requested feedback. An accessible document was used to facilitate the explanation of the findings (Appendix N). Participants engaged with this medium well and appeared to generally understand the area being described. I regularly checked participants' understanding and provided extra explanation when this was required. The difficulties originally encountered at interview re-emerged during these feedback sessions with two participants indicating that they would like to meet up again. Once again an explanation of the limitations of the researcher role and the support that they could receive from their Development Worker was received well, however, it reinforces the difficulties and reflections described within the interview process section. Another important aspect that was raised during the feedback sessions was the lack of feedback that participants typically receive from other projects that they were involved in and the positive response that people gave to receiving this in the current project. As the analysis process had taken much longer than originally anticipated the feedback was provided several months after I had originally proposed at the initial interview. I had contacted the Development Workers to keep the participants informed but several told me that they had not received this information and one participant voiced the disappointment he experienced when he had not been contacted. I felt really frustrated on hearing this as I had made every effort to ensure that participants were respected and kept up to date, to ensure they felt valued. The reflections of participants about

receiving feedback reinforced my belief in the importance of feeding back to participants and encouraging the involvement of PWLD in projects as co-researchers. Further as the feedback I received was incredibly helpful and I suspect that the project would have only been enhanced had a co-researcher with LD been involved throughout.

Conclusions

The disappointment and frustration I experienced during the many challenges faced within the research process seem to reflect the comments of Boden, Kenway and Epstein (2005) who described how inexperienced researchers are generally unaware of the 'muddle, confusion, mistakes, obstacles and errors' (p.70) that are involved in the research process due to research projects being presented as seamless and linear processes. My expectation and perception of the research process is now very different to when I commenced the project.

I am now at the end of this research journey and this commentary and I am very aware that most of my reflections have surrounded the difficulties experienced at each stage of the process, with little about the positives I feel this project and the approach have provided. I hope that by providing this reflective commentary and by maintaining a reflexive position throughout the project that the rigor and quality described at the start have been achieved. The process has certainly encouraged me to be more self reflective regarding my own perspectives and potential motives. I believe this has enabled me to look at things more critically, which is essential in research where it is understood that the researcher's role is to co-construct the findings (Larkin *et al.*, 2006; Salmon, 2003). Being self-reflective is also a fundamental part of my clinical practice, but I feel that this process has encouraged me to be more creative in reflecting, and take more time to explore my perceptions and interpretations. I hope that this process has acted to enhance the project's findings by facilitating richer interpretations, whilst also enabling an open and honest audit trail to demonstrate methodological rigor and transparency to be provided. Finally, the approach's consideration of the power differential that exists within the interview design makes it more ethical (Brinkmann & Kvale, 2005), the importance of this aspect is further enhanced by the fact that imbalances in power were identified as a significant difficulty faced by participants from their accounts. As such, I am pleased that this aspect has been fully considered throughout the research process.

Appendix M:

Response from East of Scotland NHS Ethics Service.

East of Scotland Research Ethics Service

Research Ethics Office
Tayside Allied Health Sciences Centre (TAHSC)
Residency Block Level 3
Ninewells Hospital & Medical School
George Pirie Way
DUNDEE
DD1 9SY

Ms Faye Sullivan
Trainee Clinical Psychologist

Date: February 17th 2011
Your Ref:
Our Ref: 11/GA/026
Enquiries to: Mrs Caroline Ackland
Extension: Ninewells extension 32589
Direct Line: 01382 632589
Email: caroline.ackland@nhs.net

Dear Faye,

Re: What is the meaning and experience of close relationships for people with a learning disability living in the community?

You have sought advice from the Research Ethics Office on the above project. I have considered this and can advise that this does not require ethical review under the terms of the Governance Arrangement for Research Ethics Committees (GAFREC) in the UK. The advice is based on the following documentation provided to us:

Document	Version	Date
Protocol	8-17V12	27/02/11
Participant information booklet	Draft	28/01/11
Interview Schedule	Draft	28/01/11
Consent Form	Draft	28/01/11

- You are not recruiting NHS patients
- You will require ethical review by the University of Edinburgh
- You may require ethical review by Social Services

Please note that this advice is issued on behalf of the Research Ethics Service Office and does not constitute an opinion of a Research Ethics Committee (REC). It is intended to satisfy journal editors and conference organisers, who may require evidence of consideration of the need for ethical review prior to publication or presentation of your results.

You should keep a copy of this letter within your project file.

Yours sincerely,

Caroline

Caroline Ackland
Scientific Officer, East of Scotland Research Ethics Service

Cc: Dr Allyson Bailey, R + D Manager, NHS Forth Valley



Appendix N:

Research findings feedback booklet.

Due to copyright restrictions some of the images presented within this document are different to those used with participants. All images presented here are copyright free, used with the permission of the copyright holder or are used in accordance with licensing agreements. Image sources:

- www.photosymbols.com
- www.freedigitalphotos.net
- Boardmaker (Version 6) Mayer-Johnson. LLC © (2006)
- <http://office.microsoft.com/en-gb/images>



What are close relationships like for people with learning difficulties?



What the study found out



What's in here?

What the study found out3

Relationships being safe and feeling useful.....5

Who's in charge?.....8

Struggle for an ordinary life.....12

Physical Intimacy.....16

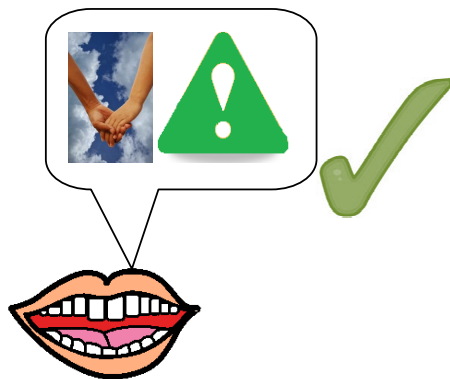
Hidden feelings.....22

If don't agree with this part of the project.....28

What the study found out

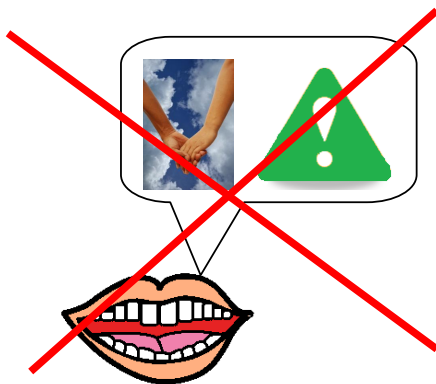
People talked about different things that were important to them.

I'm going to tell you about the main things that people talked about

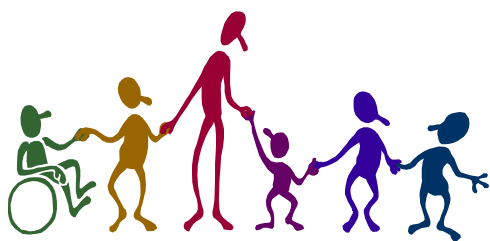


Some of these will be important to you and will be the same things that you spoke about

but

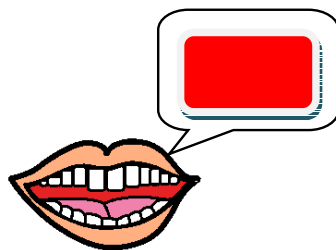
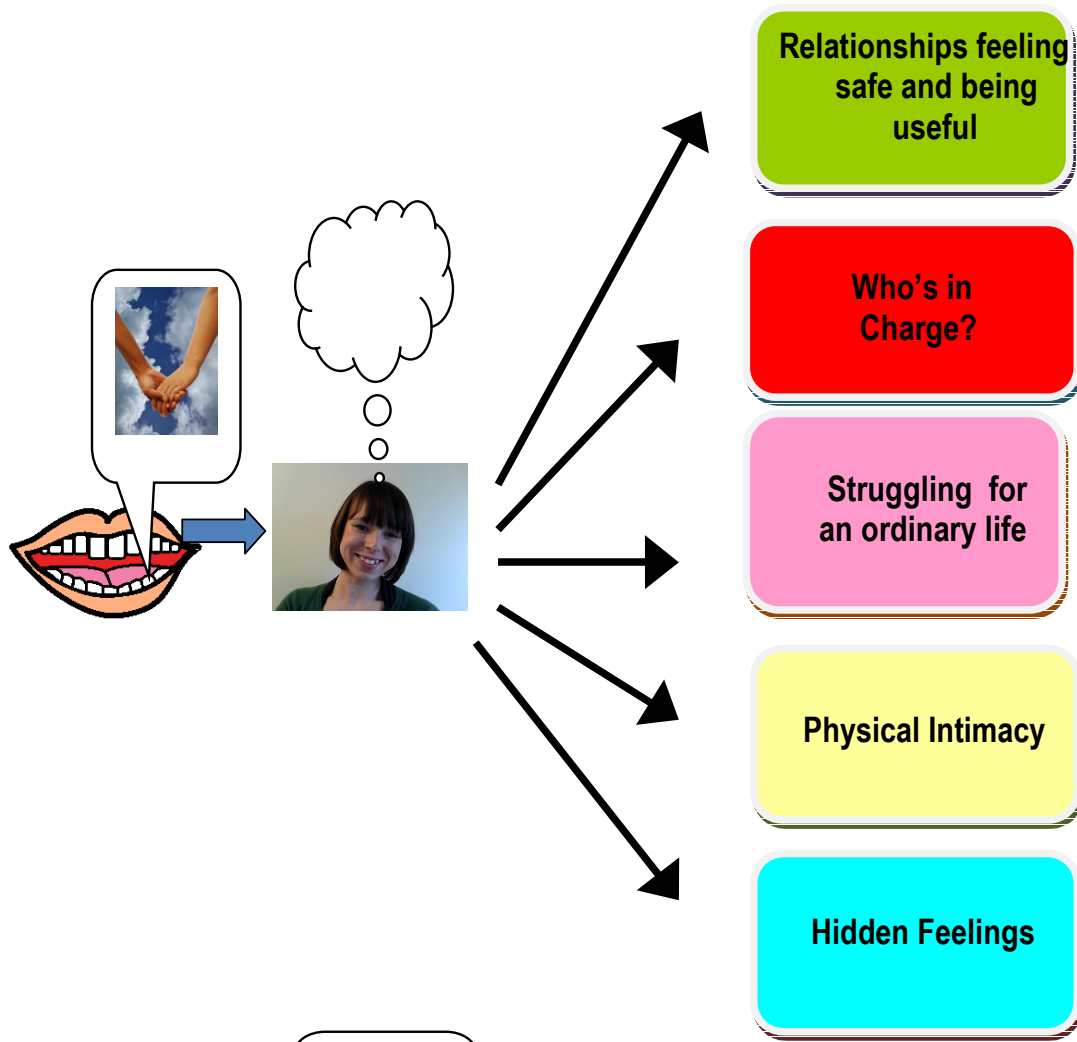


Some will not be important for you and be different to what you said.

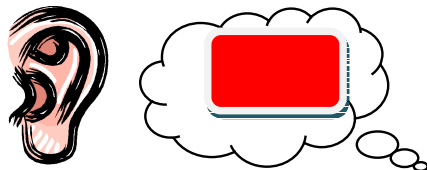


This is because everybody is different and has different thoughts and experiences

I think that there were five main things that came up when people talked about close relationships.



I'm going tell you more about these things one at a time.

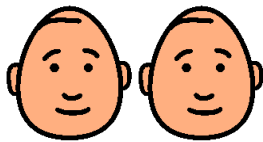


Then I would like to hear what you think about it.

Relationship feeling safe and being useful

It was important for people that relationships felt safe and were useful.

1) Relationships feeling safe



This meant that these were good relationships.

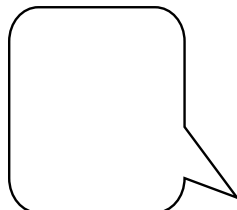


When people had safe relationships they knew the other person would:

always be there



support them when things were difficult



listen to them when they needed to talk

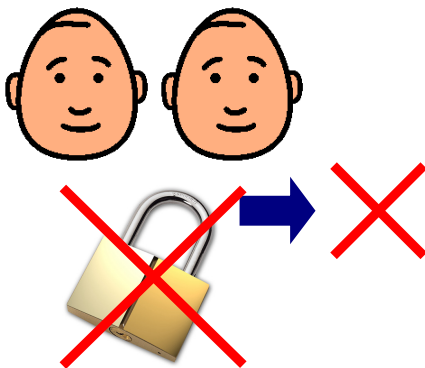


and that they could trust them. Trust meant that the other person would not hurt them

and



they would keep their secrets private.



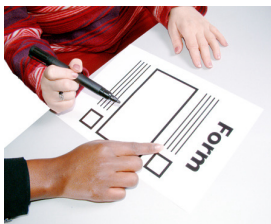
When relationships did not have these things people did not like the relationship or they found them difficult.

2) Relationships feeling useful

This meant that people got something good from their relationships.
Things that people got from relationships were:



doing things like activities or spending
time with other people



getting help

and

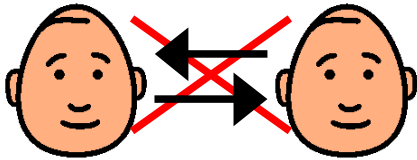


getting things like gifts like presents or
food.

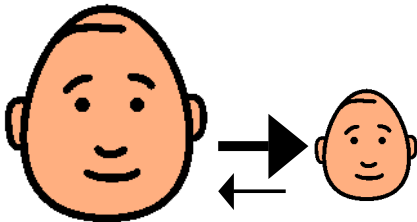
Who's in charge?

The person interviewed was not always in control of their life and relationships. This was talked about in three ways:

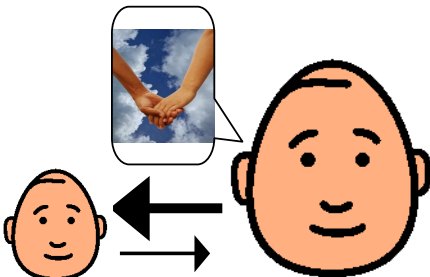
1) *One person being in charge in a relationship*



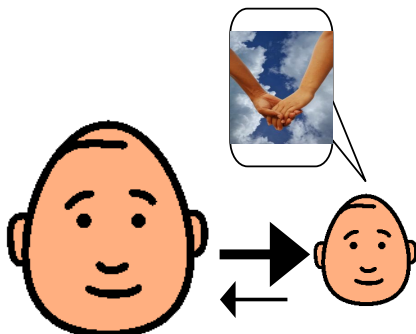
A lot of people talked about relationships where both people were not equal.



These were relationships where one person was in control.

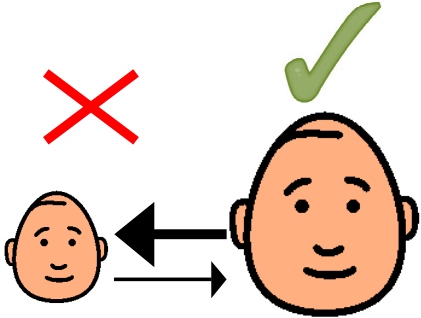


The person in control could be the person I interviewed

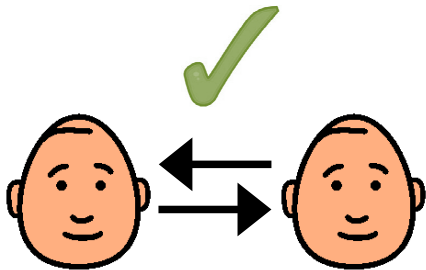


or

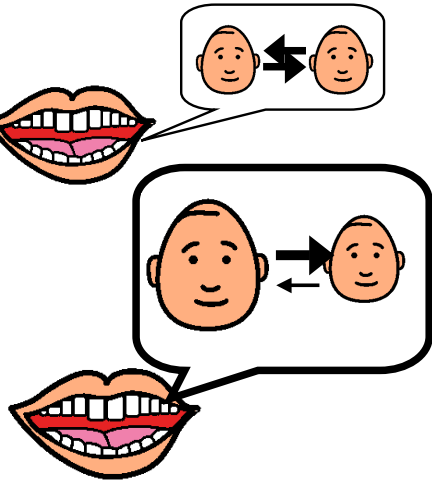
someone they had a relationship with.



People mainly liked or wanted to be the person in charge or control of a relationship.



Equal relationships were liked too.



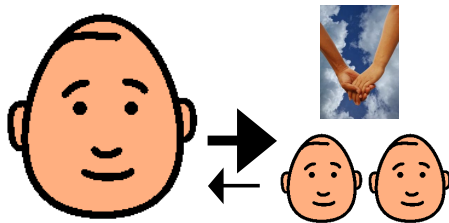
Equal relationships were not talked about as much as unequal relationships.

So

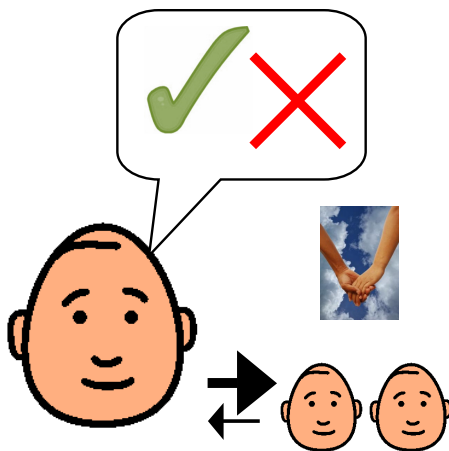
it sounds like people have more unequal relationships than equal relationships.

246

2) Other people being in charge of their relationships



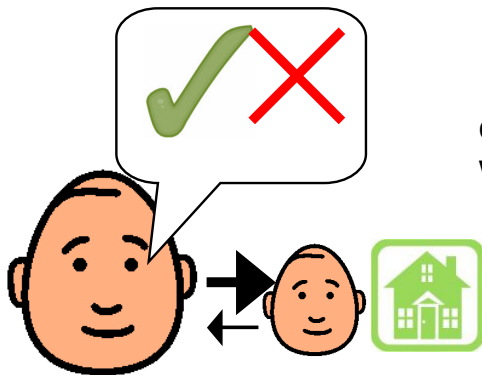
Other people being control of their relationships was talked about a lot.



People said that the other people would decide what they could and could not do with the person that they had a relationship with.

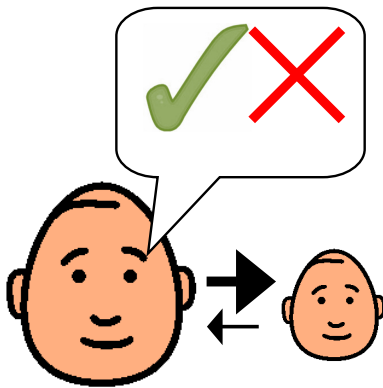
3) Other people in charge of their life

This was mainly about:



other people making decisions about where they live

or

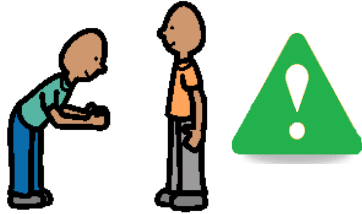


other people making decisions about what they could and could not do in their lives.

Struggling for an ordinary life

People talked about four things that they wanted in their life that they didn't always get.

1) *Being valued by other people*

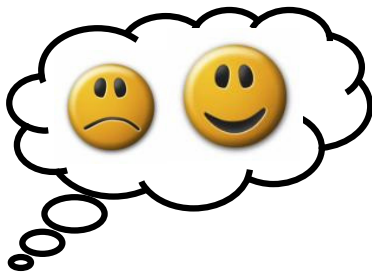


Being respected was important for people.

This meant that other people would:

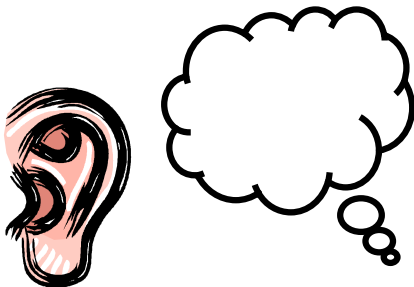


keep secrets or personal things private



think about their feelings

and

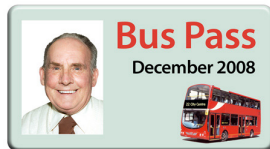


listen to what they thought

Having relationships with people who did not do this was not nice.

2) Being able to do things on their own

Doing things for themselves was important. Things like:



going out



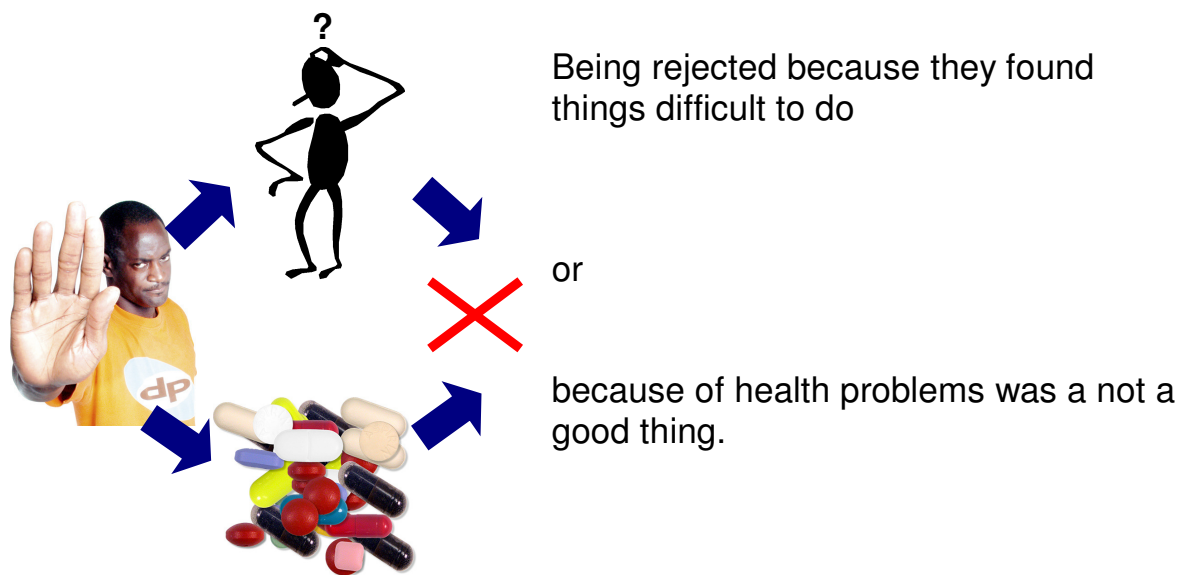
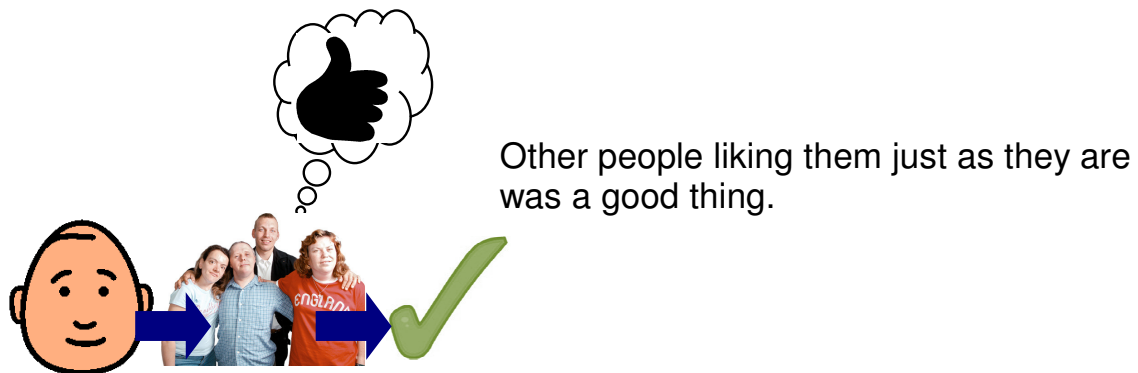
working

or

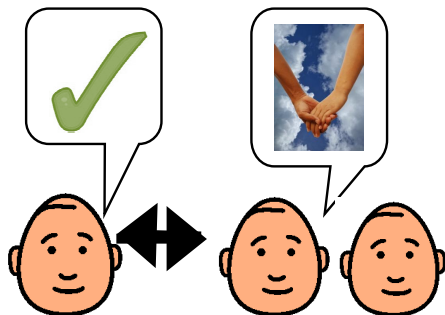


being able to talk for themselves in meetings

3) Being accepted by others

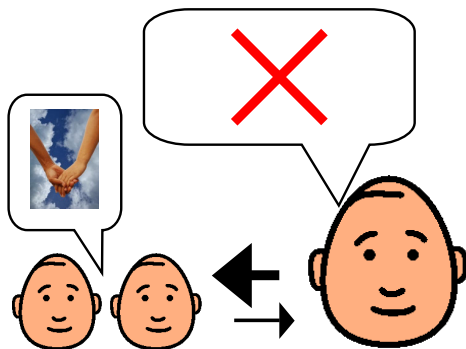


4) Being able to have a normal relationship



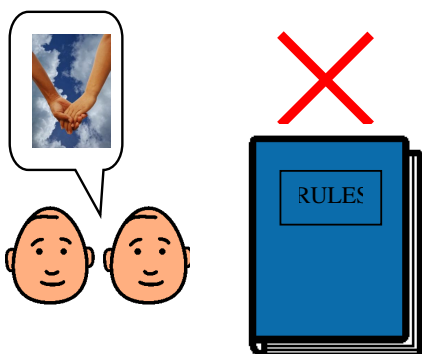
People wanted to have ordinary relationships where they were free to go and do what they wanted and that this would be ok with other people.

But



some people talked about being stopped from doing what they wanted to do in relationships by other people

or



being stopped from doing what they wanted to do by the rules of the place they lived or the services that they used.

Physical Intimacy

Physical Intimacy meant lots of different things to the people I spoke to. The main things people talked about were:

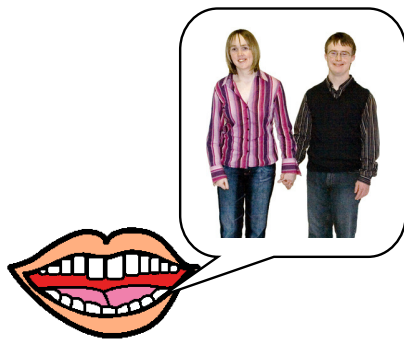
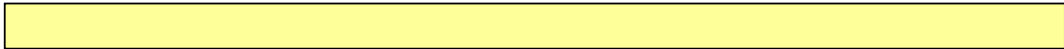


Kissing, hugging, holding hands

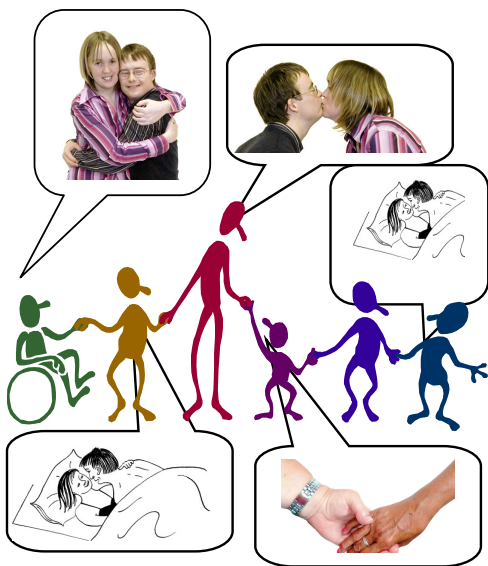
and



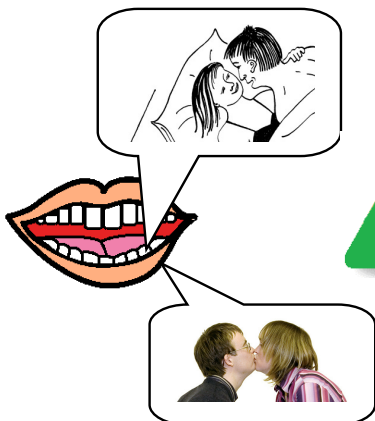
sleeping in the same place as their boyfriend or girlfriend, touching other people in private places and having sex. The last three can be called sexual behaviours.



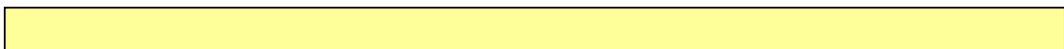
People mainly talked about Physical intimacy in boyfriend/girlfriend relationships.

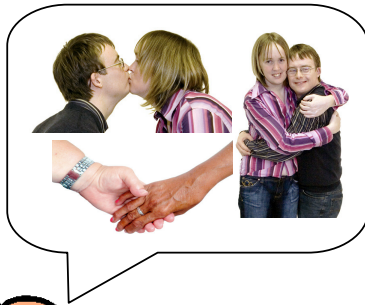
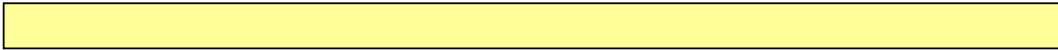


Most people talked about Physical intimacy, but it was not talked about a lot.



It seemed to be important when people talked about it.





Kissing hugging and holding hands were talked about clearly and easily by the people I spoke to.

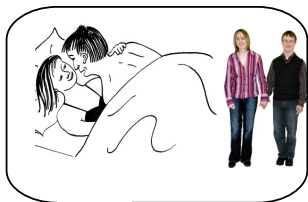


Touching each other was talked about as being a nice and important thing.

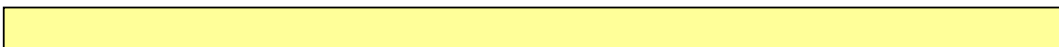
But

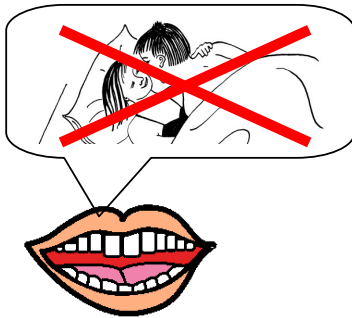


sexual behaviours were not talked about easily and clearly.



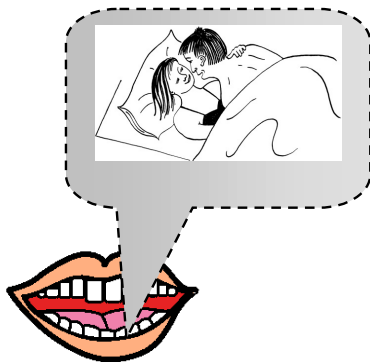
it seemed like it was not safe to talk about sexual behaviours in boyfriend girlfriend relationships.





! It seemed like this because it was **very** important for some people to talk about sexual behaviours not being part of their boyfriend and girlfriend relationship.

and



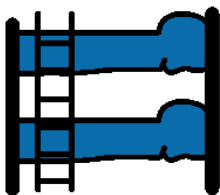
because people did not talk about sexual behaviours clearly. They suggested or hinted about these things being in their relationships instead.

Hinting and suggesting meant that people talked about other things being important that were related or linked to sexual behaviours. They didn't talk about the sexual behaviours themselves.



For example people talked about being alone with their boyfriend or girlfriend as important

or



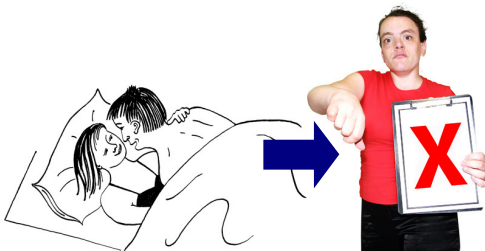
sleeping in the same room as them being an important thing.

?



People might have talked about sexual behaviours in this way so they didn't get into trouble for sexuality being part of their relationship

because



it was noticed that when people talked about sexual behaviours they were often talked about as being something wrong or bad.



It seemed like this was because of what other people had told them about sexual behaviours.



Some people had also been told off for sexual behaviours being part of a boyfriend and girlfriend relationships.

Because of this people covered up sexual behaviours. They did this by:



not telling other people they were in a boyfriend/girlfriend relationships,



or



keeping sexual behaviours a secret from other people.



It was also noticed that most of the time sexual behaviours were not talked about as a fun or nice things to do.

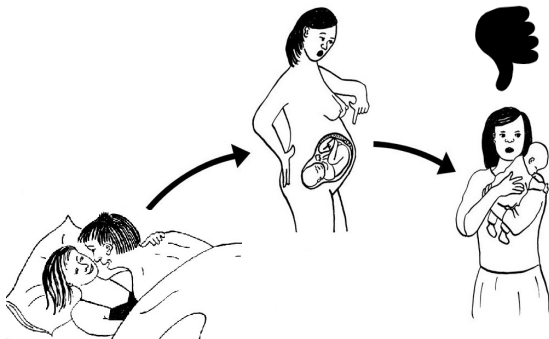


A lot of people had had bad and hurtful experiences when sexual behaviours had been part of a relationship.

People spoke about:



their feelings or bodies being hurt



having a baby, which wasn't seen as a good thing

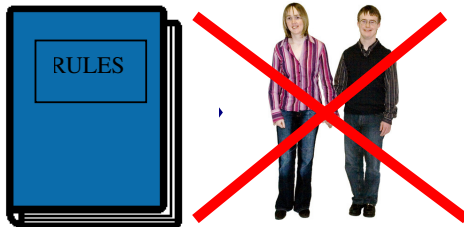
or



being told off.

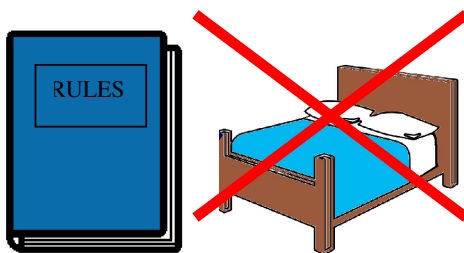
A few people also spoke about being forced to have sex when they did not want to. This is called rape.

People also spoke about sexual behaviours not being part of their relationships because of rules.



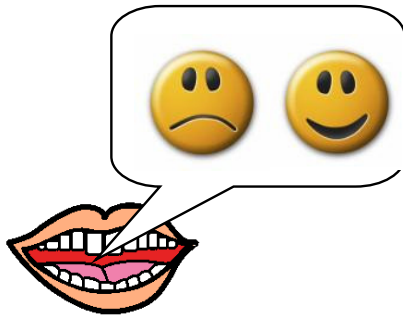
For example rules stopped people seeing each other when they wanted

and



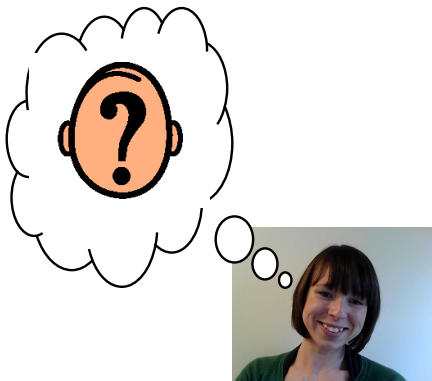
Stopped people from staying at their boyfriend or girl friends house.

Hidden feelings



People talked about feelings during interviews

but

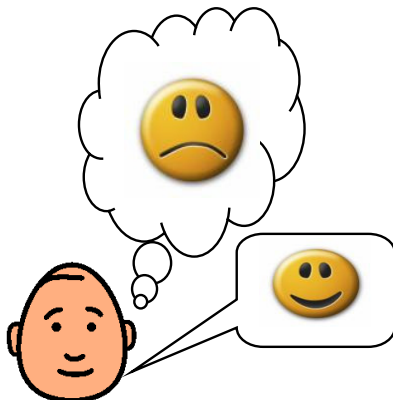


most of the time feelings were not talked about in a clear way, it was like they were being hidden a bit.



People might have been unsure talking to someone that they did not know very well

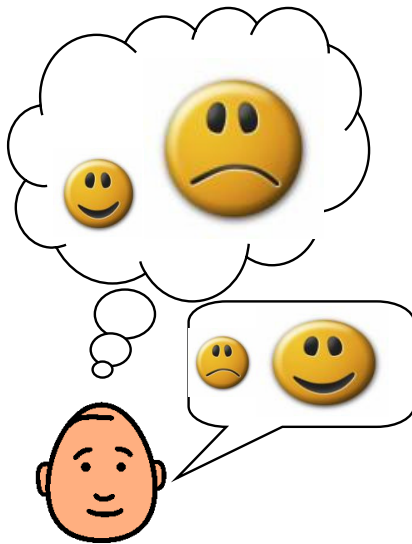
But



It looked like feelings were hidden by being covered up

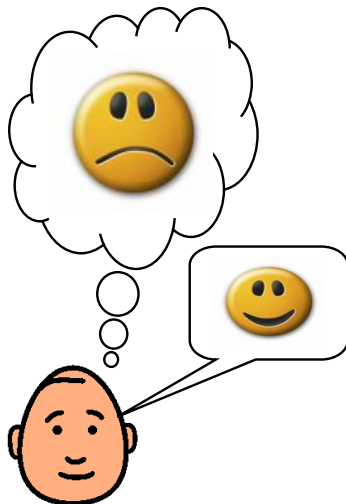


and



played down

1) Feelings being covered up

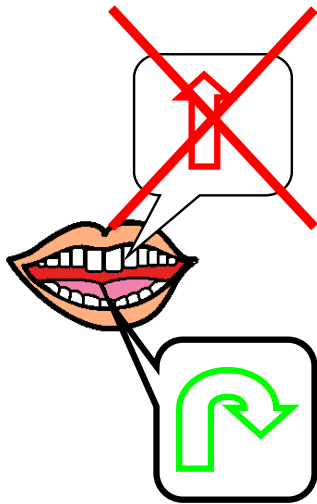


It looked like people covered up how they were feeling by:



laughing

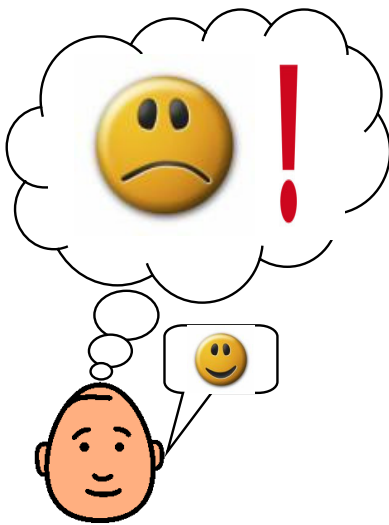




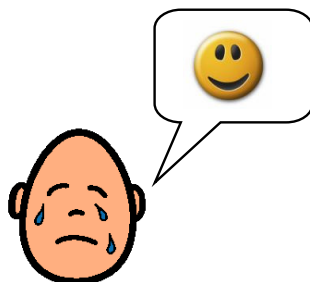
or

changing topic to talk about other things.

2) Feelings being played down



Feelings were often talked about in a way that made them seem less important than they were.

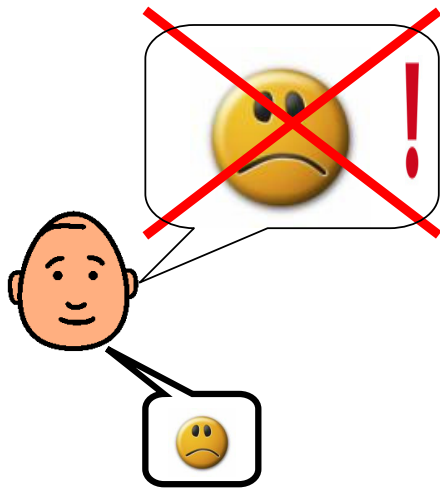


People also did this by saying they were ok when they didn't look or sound ok





or



Saying how they felt then changing their mind and saying that the feeling was smaller or less important.



**If you don't agree with this part of the project
– what can you do?**



If you don't agree with this parts of this project and want to **complain** you can do this through The University of Edinburgh.

Phone the psychology department on:
(0131 651 3972)

Appendix O (a):

**Author guidelines for Journal of Applied Research in Intellectual
Disabilities.**



Journal of Applied Research in Intellectual Disabilities

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Edited By: Chris Hatton and Glynis Murphy

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Online ISSN: 1468-3148

Author Guidelines

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1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit <http://authorservices.wiley.com/bauthor/> for further information on the preparation and submission of articles.

2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

2.1 Authorship and Acknowledgements

Authorship: Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

Acknowledgements: Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 www.wma.net) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used. Ethics of investigation: Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at www.consort-statement.org. A CONSORT checklist should also be included in the submission material (www.consort-statement.org). The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: www.clinicaltrials.org, www.isrctn.org. The clinical trial registration number and name of the trial register will then be published with the paper.

2.4 Conflict of Interest and Source of Funding

Conflict of Interest: Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

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4.1 Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.

Please upload:

1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

4.2 Blinded Review

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and **Letters to the Editor** are accepted. **Theoretical Papers** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at

http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

Running Title: A short title of not more than fifty characters, including spaces, should be provided.

Keywords: Up to six key words to aid indexing should also be provided.

Main Text: All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

- Include all figure legends, and tables with their legends if available.

- Do not use the carriage return (enter) at the end of lines within a paragraph.

- Turn the hyphenation option off.

- In the cover email, specify any special characters used to represent non-keyboard characters.

- Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

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- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

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- McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

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Appendix O (b):

Author guidelines for Journal of Clinical Nursing.

Journal of Clinical Nursing

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